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## **Learning Activity 1: Teaching Notes for Defining Healthy People & Environments Disease, Disability, & Immortality: Hope & Hype Module by Katayoun Chamany & Adrienne Asch**

In this activity students model the first two steps of the [7E model of learning](#) proposed by Arthur Eisenkraft (Engage, Elicit, Explore, Explain, Elaborate, Evaluate, Extrapolate). Students *engage* in discussion and *elicit* prior knowledge from one another by reviewing learning resource and tracing the evolution of practices and policies directed towards those living with disease and disability. The perspectives presented in the articles invite students to understand the different approaches to defining healthy people and environments including the biomedical and social models. The material reviews existing and proposed policies that have emerged as a consequence of advances in biomedical research. Additionally, the historical pieces place disability rights within the larger context of civil rights. The arguments for or against any given policy or approach address the value of social and economic capital as well as the relative value of those who live with disease and disability versus those that do not. However, the activity reminds students that everyone must confront disability at some point during their lifetime.

This activity is designed as a form of engagement and formal assessment or evaluation is not necessary. Rather, the assigned articles cover a broad overview of discriminatory practices against those that live with disability, laws to bring about equity and justice, and state and federal actions to support stem cell research, stimulating students to ask questions about current practices and future research directions. The activity can serve as segue to lectures on basic cell biology topics cell renewal, cell signaling and cell differentiation, cell death, wound healing, and neurodegeneration, especially if more references from the [Essential Resources](#) are assigned.

For students with limited biology background in biology some of the topics above can be introduced using the [ZoomGraphics and Animated Slide Sets](#) associated with this module. Instructors may choose to place more emphasis on the social context of the investigations and explore the relationship between science and other disciplinary areas such as politics, cultural studies, and disability studies.

This assignment *elicits* alternative conceptions or understandings of stem cell research and health policy. The level of discussion and the complexity of questions will vary depending on academic background and interest. The activity is designed to have students frame the discussion through reflection and the generation of a set of questions that can be answered in future class sessions.

The resources that ground this activity are reviewed by all students and review the evolution of society's address of disease and disability. These resources highlight the unique role that President Franklin D. Roosevelt played in this regard as a policy maker (Wagner O'Day Act), person living with disabilities (polio survivor), an advocate for government investment in biomedical research (National Science Foundation) and volunteer efforts combined with private philanthropy to support the establishment of the National Foundation for Infantile Paralysis, better known as the March of Dimes. This latter endeavor eventually funded the work of Jonas Salk in his development of a polio vaccine, which was tested and manufactured

in HeLa cells. This connection can be meaningful, if students are also engaged with Module 1 [HeLa Cells & HPV Genes: Immortality & Cancer](#). For the same reasons instructors may find it useful to read the first sections of the [HeLa Primer](#). The resources assigned to all students provide historical background and ask students to consider current and future research directions given this history. In the remaining resources which can be disseminated among students, the stance taken by states, such as New York and California, regarding funding for stem cell research for cures is contextualized by reviewing commentary and calls for other forms of address for those that live with disability as made by disability activists, sociologists, historians, patients, and social justice scholars.

### **STUDENT LEARNING OUTCOMES**

- Recognize how the historical and social eugenics movement contributed to increased investment in the biomedical approach to addressing cure and elimination of disease and disability in the US and UK.
- 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.
- Gain familiarity with the various arguments presented by scientists, policy makers, and social justice scholars regarding different models of health and to be aware of the diverse points of view *within* these stakeholder groups.
- Explain how autonomy, agency, exploitation, and labor are involved in disability rights and justice.
- 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.
- Present lines of evidence for and against government funding of stem cell research to address disease and disability and propose methods for proper democratic deliberation in decisions regarding resource allocation.
- Develop a set of questions about the social impact of investment in stem cell research
- Generate questions about the types of disease and disability that could be best addressed by either the biomedical or social model of health

**INSTRUCTOR PREP:** For instructors unaccustomed to introducing disability perspectives or the social model of health in their courses, it would be prudent to read the [Garland and Stull Chapter 9 from the Ethics and Public Health Model Curriculum](#) (pp. 241-251) published by the Association of the Schools of Public Health, The Health Resources and Service Administration, and the Hastings Center Institute as well as Tom Shakespeare and Nicholas Watson's article published in 2002 reviewing the history of this model as it emerged in the UK to address a form of oppression experienced by those living with disability ( ["The social model of disability: An outdated ideology" Research in Social Science and Disability, 2: 9-28](#) ).

### **FORMAT:**

Portions of this case have been used in a cell biology course, a non-majors stem cell course, and a University lecture course for liberal arts and design students at The New School.

### *Timing*

As described below, the activity can take between 1-4 class sessions wherein all students read a common set of resources that ground the activity, but then instructors may choose to use a progressive disclosure approach in which the class is split into two large groups with even-numbered resources reviewed by one half and odd-numbered reviewed by the other half. After each set of readings the instructor can facilitate discussion using the thought questions provided in the assignment.

Instructors may want to begin this module by asking students to read the one page editorial in the *Lancet* in class and elicit their responses and assign the remainder of the background resources to be completed outside of class and before the next class session. For these grounding resources the following are important to consider:

Instructors should remind students that need only to read the Letter Exchange and the Summary of the *Science Endless Frontier Report*, and they may to highlight the following questions

What is to be done in times of peace to acknowledge science used in the name of defense?  
What is to be done to address disease?  
What is to be done to foster research in private and public sector?  
What is to be done to mentor youth?

The article by Stein, is somewhat lengthy, but an essential piece to include as it provides a full social context of the culture at the time that Roosevelt served as president. Stein provides vivid detail of Roosevelt's identity shifts as he moved in and out of the public eye as part of a larger campaign strategy designed to emphasize his "fitness" to serve as president.

The book chapter by Garland and Stull is also a very helpful reference for students and instructors who are not familiar with the difference philosophies connected to fields of medicine and public health. Wherein clinical medicine involves the relationship between the individual and his healthcare provider, public health seeks to place individual rights as secondary to the rights of community or the public, a difference that can influence government resource allocation.

Though the TedX talk by Benjamin is a useful discussion of discriminatory design as related to race and class, her opening (0-6min) and ending (19-21min) as well as the title connect directly to the learning challenges posed in this module. This could be shown in class along at the start of the module along with the *Lancet* editorial.

For the remainder of the resources, if the class is split in half, with each half assigned only one half of the readings either odd (1,3,5,7,9, 11, 13) or even-numbered references (2,4,6,8,10, 12, 14) the activity can be broken up over a few days to achieve partial progressive disclosure. Using this approach would require 1-2 class sessions for Part 1. A similar approach can be used for Part 2.

### *Readings & Constructed Discussion*

The assignment can involve small group work, where each group of students is responsible for reporting out the findings of a particular news piece or video clip. The articles can be read in, or outside of class, depending on the course structure.

By splitting the class in half, the subdivision creates a situation where the two groups can discuss the same topic from different perspectives. Each group will read the views of disability rights activists, social justice scholars, policy makers, and scientists, but the complete story must be put together through structured discussion. As an example of the diversity of views within the disability community, the qualitative study conducted by Hahn and Belt (**Part 1; #6**) with members of ADAPT make a clear case of supportive care v. cure, while the observational study conducted by Quackenbush details the ways in which Michael J. Fox played a critical role in fundraising for stem cell research and how he used his disability to his advantage (**Part 1; #13**) As one example of policy perspectives, the study published by Levine at Georgia Tech and the interview with Robert Klein from the Americans for Cures (**Part 2; #1, and #5**) discuss the biomedical and economic rationale behind public funding for stem cell research in California, while the Siders et al. piece (**Part2; #2**) challenges the rationale by suggesting that an increase in social services is more necessary for immediate address of those living with disability.

There are interesting comparisons to be made as well. Instructors can highlight the cross talk between the private and publicly funded ventures of SCR in California New York using the article by Gugliotta (**Part 2; #6**). How money migrates across these two spaces can lead to further class discussion. The overall effect of the assignment is to highlight the moral dimensions of addressing disease and disability in society.

Instructors may also choose to give students time in class to form small groups of 3-5 to discuss among themselves before providing a consensus overview to the remainder of the class. For small group work, see the resources at this site ([Resource One: Group Role Profiles](#)) for role responsibilities that ensure equity in groups, or assign an “equity monitor” who must ensure that all voices are heard in the group and that any missing voices are raised.

During the class discussion, the instructor acts as note taker, guiding the discussion by posting the groups’ questions as they are posed and asking if another group can answer the question or challenge the points made using a different perspective. By asking the groups to consider how their resources “talk to one another” the discussion can move from group to group rather seamlessly. The note taking can take the form of a concept map, making explicit the connections, pushes and pulls in narratives that may appear to be in conflict, and help students synthesize a complex story from many vantage points.

### *Videos*

If instructors are using other parts of the [Stem Cells Across the Curriculum](#) modules, they may want to show, or assign, the [Ruha Benjamin TEDxBaltimore talk](#) in its entirety (45 minutes), as she uses three cases to make her point regarding discriminatory design, two of which reflect on the case of oocyte compensation for embryonic stem cell research and the disregard for the oocyte providers health and the lack of community voice in directing biomedical research using the Henrietta Lacks case.

Three teachable moments emerge,

#### *Living with Disability*

Most students have little understanding of disability and disease as it relates to their daily activities. Reading the first person narratives and biographical pieces may make some students very uncomfortable. They may not be aware that not all buildings are made accessible, that disability is a category of “other” that is least addressed during conversations regarding minority status, and that civil rights for African Americans and women came before rights for those living with disability. Reading about the dependencies that are created through social practice and policy will help students see that despite the ADA, barriers to work, community engagement, and adequate health care continue to exist. Moreover, it is important that students be made aware that most patient advocacy group are not necessarily representing those that live with disability but, more often, are led by the parents or relatives of those living with disease or disability. In other words, students should distinguish among those organizations for people with disabilities and those that are comprised of people living with disabilities. Lastly the timing, the severity, and the frequency of disability can influence how one views the utility of the biomedical approach. For instance disability rights scholar and advocate Tom Shakespeare believes that static conditions such as spinal cord injury could be better served by the social model of health while degenerative diseases such as Parkinson’s and Alzheimer’s may be better served by the biomedical model. Many of the conditions for which stem cell research (SCR) seeks to develop treatment are late-onset, as well as intermittent, progressive, or degenerative. Because conditions like Parkinson’s and Alzheimer’s cause the loss of valued functions and the disruption of valued activities and commitments, there is a strong case for giving their treatment higher priority than the treatment of congenital blindness or deafness. But it is also important to recognize that there are vast differences among the conditions, and individuals, that SCR

seeks to benefit, and that these differences will affect the urgency, and even the appropriateness, of SC treatment. Shakespeare makes this explicit in [a piece for the Guardian](#) reviewing the goals of a new initiative Drill (Disability Research on Independent Living and Learning):

Research has been key to the progress disabled people have made since the 1970s. Back then, disability rights pioneer Paul Hunt labelled academics “the parasite people”. In response, the disability movement created the concept of emancipatory research. As a result, effective partnerships between academics and activists made the case for self-operated care schemes and for anti-discrimination legislation...

Underlying Drill will be partnerships between disabled people’s organisations and researchers, with disabled people involved at every stage. Drill is consulting on the themes that have initially been drawn up for the research programme. There are three cross-cutting themes: autonomy, peer support, and resilience; and a cluster around social citizenship, economic participation and civic participation. ([Shakespeare, 2015](#))

### *Eugenics, Discrimination, & Social Justice*

For many students, eugenics is an abstract concept, and rarely associated with current notions of disease and disability or human variation. In the past eugenics was a social phenomenon imparted by society on a population, preventing them from passing on “bad genes” to future populations. More recently, an individualized eugenics has emerged alongside reproductive technologies that allow families to control which genes they pass on to their children. This sort of “flexible” eugenics, as coined by medical anthropologist Rayna Rapp, is becoming more mainstream. In the blog post by Nee’am (**Part 1; #14**) the notion of embryo screening for various genetic associated diseases and behaviors is raised and challenged given the multifactorial nature of most neurodiversity. Nee’am and others see the use of these technologies as a new form of eugenics. To help students tackle potential discriminatory practices in the future several resources in this activity highlight the stigma past and present that accompanies disability. The elegant feature in the *New York Times Magazine* authored by disability advocate Harriet Johnson details her own struggles to navigate her role as an advocate for her community while maintaining a conversation with someone who has openly threatened her identity (**Part 1; #5**). Other instructive examples are highlighted in the pieces addressing language, the past use of social eugenics in the US and UK, and the personal experiences of those who attempt to “pass” as seen in the biography of Roosevelt as told by Stein and the identity shift in Michael J. Fox as he continues to advocate for Parkinson’s Disease research as described by Quackenbush. The resources from the *Chronicle of Higher Education* that address barriers to education can be seen as a sort of social oppression. Levels of education often correlate with economic advantage, and better health outcomes.

### *Resource Allocation & Democratic Deliberation*

Most disability activists are not opposed to biomedical approaches to health but feel that the heavy emphasis crowds out other points of view. As quoted in the Garland and Stull Chapter:

“For example, in the last twenty years, neonatologists have made remarkable strides in delivering effective care to endangered neonates. Yet during the same period, rates of prematurity and low birthweight have been rising. A narrow focus on medical care access and allocations prevents society from focusing on social and economic factors that lead to these birth conditions. As a matter of social wisdom, the public health frame will look for some way to

reduce this increasing flow of patients to costly neonatal intensive care units (Lantos 2001).” (p 245)

“Moving from the ethics of access to the ethics of allocation of resources calls for careful attention to the data on which policy makers rely. Allocation of resources in pursuit of access requires the ability to achieve valued outcomes in sustainable systems. The systems have to distribute benefits and burdens fairly. To do this, society must have a way to determine the relative value of specific interventions in medical care and health protection efforts. Society also must be able to assess the relative value of various health-related institutions in the light of their effect on the general health status of the community and their contribution to the compassionate response to disease, trauma, and care for chronically ill or dying persons. To manage health care systems in pursuit of solidarity, wisdom, and fairness, leaders need data from quantitative epidemiology (knowledge of the distribution of disease and identification of probable causes). Quantitative data is useful but not enough to guide ethical discourse at the policy level. Complementary qualitative data from the stories of individuals living out health care relationships with one another and among various social institutions help policy makers understand the human value dimension of health care organizations. The capacity to care simultaneously for individuals and the community drives the assessment of needs and services. Knowledge of the values of the community related to health and illness should guide the social ethics of health care provision. Scientific knowledge and technical capacity determine how society can respond to health protection opportunities and threats.” (p 248)

“Experts in economics, insurance, epidemiology, clinical care, and public health have specialized knowledge relevant to health policy design. Data and expert opinion from these sources are essential to rational policy choices. Providers of special expert information, however, do not constitute the appropriate source for the articulation of community values. As members of the community, these technical experts represent only a narrow segment of the population. They are not a representative group. They tend to define problems from their specialized field. This leads to putting the perspective of the special field ahead of the values of the community. Priority should be given to articulating the social goals valued by the community. With a clearer view of these values, the experts can help leaders find the most effective or efficient way to achieve society’s goals. The distinction between means and ends is an important one to bear in mind throughout the policy development process.” (p 250)

### **CONTEXT and EXTENSIONS:**

If used in a freshman seminar, *People’s Science: Bodies and Rights on the Stem Cell Frontier* by Ruha Benjamin could be assigned, as it depicts the ways in which stem cell policy in California is viewed by various stakeholders including those who advocate for disability justice, the social model approach to health, and economic equity. If this activity is used in a course on transhumanism, disability studies, or one that questions the very notion of “normal” the film *Fixed* would illustrate the ways that emerging and adaptive technologies are moving those who might be viewed as disabled and superabled, or enhanced. The trailer for the film raises this point quite effectively and additional documentary films are available at the [Disability, Adaptation, and Enhancement Video Guide](#) associated with this curriculum.



1. Benjamin, R. 2013. *People's Science: Bodies and Rights on the Stem Cell Frontier*. Stanford: Stanford University Press.272. [Link](#)
2. Benjamin, R. 2014. Race for cures: Rethinking the racial logics of 'trust' in biomedicine. *Sociology Compass*. 8(6): 755-769 [Link](#)
3. *Fixed: The Science Fiction of Human Enhancement*. Brashear, R. (Director). 2013. Making Change Media. [Trailer Link](#).

**FURTHER LEARNING:** Instructors and students would benefit from following this engagement activity with [Learning Activity 2](#) (Explore, Explain) and [Learning Activity 3](#) (elaborate, evaluate, extrapolate) to be posted in 2016. A collection of **Discussion Questions, Timelines, PPT slide sets, Essential Resources, and Infographics** tracing the trajectory of technologies and policies are also available in this [module](#). Additionally, the [Artworks](#) and [Videos](#) section of SCAC offer more resources.