Chapter 11

Defining and Analyzing Disability in Human Enhancement

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ABSTRACT

Human Enhancement Technologies (HET) offer valuable assistance for individuals with disabilities. Alongside these opportunities, it is important to consider the ethics that inevitably emerge. The field of disability studies recognizes that disability is a key aspect of human experience and that the study of disability has important political, social, and economic implications for society as a whole, including both disabled and nondisabled people. This chapter raises ethical questions about HET for disability through review of the literature surrounding this topic. To evaluate the ethical implications of regulating enhancement technologies for disability, medical and social models of disability are applied towards select cases. This chapter responds to the work of select disability scholars (see Dolmage; Kerschbaum & Price; Meloncon & Oswal; Vidali) by characterizing ethical perspectives from medical and social lenses. While a medical interpretation of disability offers a stark and impersonal approach, a social interpretation offers a detailed and individualistic one. The majority of scholarship noted here favors the social model. The framework presented herein seeks to abide by the social model of disability. Since HET have become an ethically contested field of discourse today, this chapter divides the literature into the following sections: 1) definitions, distinctions, and challenges of medical and social models of disability; 2) ambiguity, authenticity, and the ab/normality construct; 3) forced privacy and the privilege to hide; and 4) recent trends in regulation and the ethics of development.

DEFINITIONS, DISTINCTIONS, AND CHALLENGES IN SELECT MODELS OF DISABILITY

It will be useful to explore some of the theoretical constructs prevalent in disability studies. A starting point exists within an academic context, in which disability has progressed from exclusivity to one that is more inclusive via diverse pathways. The composition classroom proves to be an intellectual starting point for critical thinking, so it should come as no surprise that the social model of disability has its roots in rhetoric and composition. Shannon Walters (2011), for example, defines

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the social model as one that “led people with disabilities to write about their own experiences of disability [by resisting] dominant medical discourse” (p. 430). Walters’ point is to say that the very notion of disability has become defined as a burden upon society. To work through this unfortunate circumstance, scholars like Palmeri (2006), Slatin (2001) and Zdenek (2009) stipulate that new media has potential for incorporating methods for all students alike, regardless of disability status. The point here is to recognize that technology attempts to universalize the learning experience, albeit not always successfully.

The University of Leicester hosts a number of doctoral and postgraduate research initiatives that promote the view of disability through the social model. In line with Walters’ argument (2011) described above, Leicester defines the social model by drawing on the idea that “it is society that disables people, through designing everything to meet the needs of the majority of people who are not disabled” (Student Support Service, 2008). The social model calls for responsibility through interdisciplinary research; along these lines, an ideal scenario envisions a research area like transhumanism to “to locate itself not in response to changing hostile geographies but as a proactive architect of future possibilities” (Dolmage, p. 25). Dolmage’s point is to say that people with disabilities should not be expected to change what is beyond their control, but to actively foresee and work around potential issues.

The social model has not come without its problems, however, as the very definition of disability is debated: Shakespeare (2006) extends this argument by explaining “the social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem” (p. 200). Disability-specific tools such as educational podcasts for vision-impaired students may solve problems on a case-by-case basis, as Zdenek (2009) maintains, but such tools lack a comprehensive change of pedagogical practices. While podcasts may not be a form of HET, the point is that technology’s attempt to universalize the learning experience is unsuccessful. The concept of Universal Design, or UD, asserts that practices designed for students with disabilities should benefit those without disabilities as well (Center for Universal Design, 2008a). Just as UD attempts to help students across the board, regardless of disability status, problems become much more complicated on an everyday level. For instance, what if a website that purports to be accessible to visually impaired users malfunctions? Or, to ask the question more broadly, what is an ideal situation for all learners/users, regardless of disability status?

The medical model seeks to answer these questions, although in doing so it offers an impersonal method of approaching disability. To delve into the medical model further, the Michigan Disability Rights Coalition offers the following critique:

[The medical model] has dominated the formulation of disability policy for years. Although we should not reject out-of-hand its therapeutic aspects which may cure or alleviate the physical and mental condition of many disabled people, it does not offer a realistic perspective from the viewpoint of disabled people themselves. To begin with, most would reject the concept of being “abnormal.” Also, the model imposes a paternalistic approach to problem solving which, although well intentioned, concentrates on “care” and ultimately provides justification for institutionalization and segregation. This restricts disabled people’s opportunities to make choices, control their lives and develop their potential. (Michigan Disability Rights Coalition)

At its core, the medical model envisions disability through a skewed lens. Disability is viewed as being out of the norm. A disconnect is created which may be characterized as being part of an able-bodied versus abnormal spectrum (Price, 2011). As a result of this disconnect, people are defined through their disabilities. Responsibility