Disability Studies: Origins, Current Conflict, and Resolution Elizabeth DePoy, Ph.D. & Stephen Gilson, Ph.D. University of Maine

Abstract: In this article, we identify the roots of disability studies in interdisciplinary intellectual traditions as the basis for its current creativity, as well as its challenges in serving multiple academic masters. Looking to the future, we suggest rethinking and teaching disability through an integrative, interactive framework of juncture/disjuncture.

Key Words: disability theory, interdisciplinary, diversity theory

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Introduction

Over the past four decades, academic attention to disability has undergone significant change and thus, has provoked debate about how higher education should interrogate and teach about disability. Challenging embodied medical deficiency as the essential characteristic of disability, the relatively new interdisciplinary field of disability studies has synthesized interdisciplinary thinking from multiple academic and professional arenas, including humanities, arts, social science, and natural sciences to inform definition, analysis, and response to disability. Not unexpectedly, the emergence of disability studies has been a multi-edged sword, creating both advancements in intellectual treatment of disability along with disagreement, conflict, and fractious argument among diverse academic and professional disciplines. If disability studies is to enthrone and disambiguate progressive inquiry and responses to diverse bodies, we suggest that the field not only can, but also must serve multiple academic masters within current higher education environments and their diverse purposes. We therefore begin our discussion by clarifying the context in which disability studies lives – the current climate, scope, and purposes of higher education. We then look to recent history to trace the intellectual and professional path of disability definitions and theory. Anchored on this brief historical foray, we then propose a conceptual integrative approach to disability that is relevant to the multiple purposes of higher education and serves the varied bodies and experiences that have permeated the categorical boundaries of disability.

Higher Education Clarified

Similar to other institutions, universities are not immune to their knowledge, geographic, economic, political, and social contexts. And thus, while the primary purposes of universities are ostensibly the generation and transmission of knowledge, the advanced capitalism of the 21st century along with the erosion of public support have been a major impetuses in reshaping universities as complex, market-based entities rather than fortresses of intellectual life (Allen, Bonous-Hammarth, & Teranishi, 2006). Responding to these economic trends for their survival and growth, universities have turned to academic capitalism, or the implementation of business practices to redefine

core functions of education, research, and service as products to be marketed and sold. However while economically relevant, academic capitalism has been indicted by many as one of the major factors that has obfuscated the intellectual purposes of higher education and that has created significant challenges in its wake for established as well as fledgling fields (Slaughter & Rhoades, 2004).

We suggest that higher education can maintain its intellectual integrity and provide a sound academic, as well as professional, foundation for disability studies within an advanced capitalist context. We agree with Sullivan and Rosin (2008), who have proposed a model of "practical reason" as a contemporary framework for higher education that meets these aims. Curiously, this academic model, while hailed as new, is reminiscent of progressive thinkers of the 20th century such as Dewey (1916) and Eisner (1985). In concert with these seminal philosophers, practical reason is bounded within a teleological framework, that of integrating intellectual development anchored in the liberal arts with informed career and civic preparation for students. This scaffold provides a buttress against which disability studies can be solidly anchored as a field that not only serves, but also unites both academic and professional purposes within an intellectual tradition. However, this ideal is not currently in operation in most universities and scholarly societies that are concerned with disability studies.

Disability: Multiple Theories and Stewards

Although disability has been the object of curiosity, observation, and formal study for centuries, the academic field of disability studies is nascent, having been born and named approximately two decades ago (Davis, 1997; DePoy & Gilson, 2004). Countering research and teaching about disability as a medical deficit in need of repair or rehabilitation, disability studies scholars and activists in the late 1980s and early 1990s explained disability as a social phenomenon, in which the concept of normal was constructed, and those whose embodied appearance or experience did not fit within it, were subject to cultural discrimination and exclusion (Davis, 1997; DePoy & Gilson, 2004). The introduction of the social model of disability was an important impetus in conceptually moving disability away from medical deviance and hegemony into the discourse of human construction, diversity, and discrimination. However, an unintended consequence of this theoretical shift was the creation of opposing explanations and academic stewards that cleaved the study of disability into academic and professional camps as depicted in Table 1.

Scholars in social sciences, arts, and humanities eschewed medical-biological perspectives from the new field, asserting that these approaches were not only outdated, but diminutive and exploitive of the large number of people who meet the eligibility criteria for disability. Still, many faculty and researchers in professional and health care fields, because they were concerned with disability, adopted the term "disability studies" as descriptive of their purview, despite their frequently articulated perception of nonacceptance in disability studies scholarly and activist organizations.

Along these same lines, while not the only groups to address disability studies, two major organizations in the U.S., each with different purposes and conceptual foundations emerged, the Society for Disability Studies (SDS) and the Association of University Centers on Disability (AUCD). As a leader in disability studies scholarship situated in liberal arts, SDS advanced the guidelines in Table 2 in an effort to codify the essential elements of disability studies, omitting natural and medical sciences as definitive with the exception of interrogating the link between medical views and stigma. The Association of University Centers on Disability (AUCD), on the other hand focused its activity on supporting a network of extramurally funded centers in universities devoted to research, training disability policy and professional practitioners, and linking universities to communities through informed service.

More recently, in response to the chasm that even today continues to polarize disability scholars, several theorists have advanced integrative and axiological frameworks through which to understand disability as a complex set of value-based and purposive explanations that are posited for the atypical and which can inhabit the same explanatory space as friends or foes (DePoy & Gilson, 2004, 2008; Gilson & DePoy, 2008; Slingerland, 2008). This thinking fits well within the current academic climate and is consistent with the model of practical reason advanced by Sullivan and Rosin (2008).

Integrative theories focus on challenging the dualism that separates the physical world from the world of ideas. While not directly addressing disability studies, Slingerland (2008) is a vocal critic of postmodernism and its conceptual distance, as well as distinction from natural science. Through his analysis of how cognitive science can inform culture and cultural studies, typically thought of as the domain of humanities and social sciences, Slingerland illuminates how sciences and humanities have much to contribute to one another. Similarly, fields such as literary Darwinism (Caroll, 2004) link humanities and sciences in a potent explanatory dialog.

Axiological frameworks, and here we focus on Explanatory Legitimacy, which explains diversity group membership and response as a function of how varied reasons for human phenomena are ascribed and judged (DePoy & Gilson, 2004), provide a discourse platform on which many explanations can be laid and then examined for their legitimacy. Making room for pluralism of purpose and thus explanation, eliminates the debate about which theory is correct, and through abductive logic, opens thinking and dialog for cooperation rather than competition among schools of thought (DePoy & Gilson, 2007). As examples, expressive fields such as literary criticism have different aims than health professional fields in interrogating disability, each guiding the valuation and selection of different explanatory theories of disability within their teleological boundaries. However, while purpose differentiates direction, its beauty lies in its acknowledgement of the truth-value of alterative explanations that although not primary in attaining specified aims, can inform and enrich analysis of disability.

Evidence of the positive influence that integrative and axiological theories have had on the relaxation of rigid lines within the stewardship of disability studies are the recent links to SDS added to the AUCD website and the increasing reference to disability

through the aperture of arts and humanities in professional academic programs. These integrative trends not only create the opportunity for dialog and sharing of current thinking, but also are fertile for the generation of new seamless theory. Within the framework of explanatory legitimacy, we now discuss disjuncture theory (DePoy & Gilson, 2008) as explanatory of disability and demonstrate its potential to unite disparate thinking, academic stewards, learning aims and outcomes, and social action.

Disjuncture Theory

Figure 1 depicts disjuncture theory and its opposite, juncture. The word "disjuncture" is defined as a disconnected relationship between at least two entities. Conversely, juncture refers to a relationship of connection and goodness-of-fit. Applied to disability, disjuncture theory traverses disciplinary boundaries and indicts the ill-fit of humans and multiple environments as explanatory of disability. Thus, unlike the binary debate about the correctness of disability as either embodied or environmental, disjuncture holds neither element as solely responsible but rather highlights the relationship between the two as the explanatory locus. This relational gaze not only halts the ongoing argument about the true nature of disability, but furthers the pluralistic opportunity for dialog and cooperative thinking and action among diverse fields. Considering disability as a function of both bodies and of environments therefore can bring multiple fields of knowledge to bear on healing disjuncture without dismissing the contribution of either the body or the environment to the explanatory repertoire. In addition, the term disjuncture does not demean the atypical body but rather looks to a less than satisfactory relationship between individuals and one or more types of environments as the target of change.

<u>Figure 2</u> provides a graphic representation, using the problem mapping model (DePoy & Gilson, 2007) to depict the contribution and relationships of diverse academic and professional fields to disjuncture. The problem mapping process is a thinking method to expand a problem beyond its original conceptualization. One posits an initial statement (in this example disjuncture) and them maps upstream to theorize causes, and downstream to identify consequences. The value of this conceptual map is its movement beyond first impression to the creation of an integrated systemic approach to understanding problems as multidimensional, nonlinear, and complex. Let us look in more detail at each element now.

The two text boxes on the top of Figure 2 represent the two prevailing and often conflicting causal models of disability, embodied and environmentally constructed. Note that they are connected with a broken arrow to depict their limited interaction. The term embodied broadly refers to the organic and experiential human corpus. Included are the sensory body, the cognitive body, the socialemotional body, the spiritual body, the economic body, the productive body, the body of ideas and meanings, and the body in multiple garb and spaces (Gilson & DePoy, 2007). Within explanatory legitimacy, the atypical body catches attention, and depending on the explanation for what is atypical, may or may not be classified as disabled. Bodies that do not conform to prescriptive averages, are challenged to participate in environments in which they do not fit (See Figure 1). And as depicted in Figure 2, embodied elements of disability become, in large part, the province of professional attention, assessment and, if possible, repair. Within professional education in fields such as medicine, health, special education, and so forth, studying and learning to heal disjuncture means remediating embodied deficits or making

accommodations to permanently impaired bodies so that they can function in unchanged environments.

Environment refers to sets of conditions external to bodies, including but not limited to, physical, sensory, social, virtual, expressive, economic, policy, cultural, national, linguistic, global elements, and so forth. Figure 2, links these to the examination of environmental incapacity to meet diverse bodies. Because current built, virtual and abstract environments explicitly or implicitly conform to standards based on theoretical averages, a full range of diverse bodies, and particularly those that lie beyond typical appearance, behavior and experience often are met with discomfort at best in numerous environments. Even within the diversity rhetoric of the 21st century, it is curious to note that architectural, social, virtual, professional, policy and functional design standards operationalize theoretical, male-centric averages (Imre & Hall, 2001). As examples, our recent inquiry into the rationale for and derivation of architectural standards for door sizes, counter heights and the like, revealed the continued hegemony of DaVinci's Vitruvian man as both the foundational ideal and basis for estimating average adult body sizes. This elongated misogynist adult image is the design bedrock for mass-produced and standardized building and product design practices (Gilson & DePoy, 2007). Similarly, assumptions about typical bodies, such as the ability to use both hands for manipulation, to think typically, to behave in an expected manner, to walk with a typical gait, to hear, to see, etc., provide the prevailing data on which design of varied environments is anchored. As depicted in Figure 2, environmental conditions and change are primarily the purview of liberal arts academic fields (e.g., sociology, music, art, communication theory, new media, among others) that may consider bodies, but do not direct full attention to improving their functionality.

By accepting the explanation for disability as relational, that is to say, an ill-fit between embodied phenomena and the environments in which bodies act, the opportunities for multiple fields, in collaboration with one another, to posit the complexity of disability and thus, enlarge the range of legitimate responses becomes boundless. Figure 3 represents this theoretical state of juncture. Disjuncture theory creates a conceptual forum for creative and progressive thinking, and action that expand analysis of disability beyond atypical embodied phenomena to the creation of juncture through the reciprocal relationship of diverse bodies and environments. Moreover, within this theoretical perimeter, juncture refers to equality, human rights, and justice that can be advanced through multiple response avenues.

Thus, in addition to transcending the binary medical-social model debate that is focused on impaired bodies and their treatment in environmental milieus, disjuncture theory guides purposive, legitimate human rights responses that have the potential to engage the interests, values, knowledge, and expertise of multiple fields in healing disjuncture for all populations. Disability, while possibly being related to atypical bodies, may also indicate a broader state of ill-fit, locating disability squarely within theory, examination, teaching, learning, and social action aimed at social justice, rather than restricting it to remediation of an embodied condition through bodily treatment or environmental revision. Table 3 lists just some of the diverse fields that can collaborate in the academy to examine disjuncture as the basis for decreasing and forging directions to eliminating it.

In concert with contemporary rethinking of the academy and its purposes framed by the model of practical reason (Korner, 2001), the principles listed in <u>Table 4</u> guide interdisciplinary inquiry and pedagogy, transcending the stale binary body-environment debate and positioning disability studies within a larger, collaborative, human rights academic agenda.

Resolution

To conclude, we discuss an example of the implementation of disjuncture theory. Over the past two years, we have engaged students in an ongoing project to promote equality of access to web-based health information. This project, framing and organizing several of our interdisciplinary disability studies courses, involves the design, development, testing, and dissemination of a website that translates existing health information into alternative literacy and accessible formats, regardless of the features on the original website. Currently, the project, is funded by the American Legacy Foundation (www.americanlegacy.org), as it uses the webportal to translate electronic smoking cessation information. Students and faculty from the fields of design, health and human service professions, education, art, computer science, English, and marketing are collaborating in diverse roles on this work.

Applying disjuncture theory to the project, barriers to information access are analyzed through problem mapping (DePoy & Gilson, 2007). These violations of human rights to information, and in this case health information, are serious, complex and cannot be resolved by monistic approaches, such as legislation or policy promulgation that are currently in place, but ineffectual in their stated aims. While the explicit access barriers are located at the intersection of bodies and the virtual, textual environment, problem map analysis of the disjuncture, as depicted in <u>Figure 4</u>, reveals the unpacked complexity of the initial problem statement. <u>Figure5</u>, illustrates how disjuncture was approached and addressed in interdisciplinary study and response.

Note that in Figure 5, cognitive impairment and immigrant status are not changed but attention to these embodied phenomena as well as to the environment is a function of the intersection and collaboration of multiple fields. Moreover, consistent with the practical reason model, education using a disjuncture framework aided by problem mapping has multiple purposes and stewards.

As the 21st century proceeds, we envision the future of higher education as a context in which thinking and action transcend the rigid disciplinary boundaries that produce unfruitful debates about which theory is the truth. Within a purposive context, disability can be reconceptualized and met with socially just responses that require not a village of like-minded people, but an informed universe of varied perspectives and responses.

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Table 1: Multiple Stewards, Multiple Purposes

Stewards	Purposes
Professional Education	Professional training in medicine, special
	education, social work, rehabilitation,
	architecture, etc.
Workforce Development	Continuing education and training for
	providers
Social Sciences	Examination of social and political issues
	raised (e.g., Baby Jane Doe, human rights,
	physician assisted suicide, etc.)
Arts and Humanities	Disability as representational, as embodied,
	as fabricated, as narrative of the body,
	depicted in media, designed

Table 2 Guidelines for Disability Studies Programs posited by the Society for Disability Studies (2004).

- Content: A "humanities, sciences, and social sciences" field
- Purpose: Should interrogate the connections between medical practice and stigmatizing disability
- Who leads: Leadership positions held by disabled people
- Who teaches: Academic faculty

Figure 1 Disjuncture/Juncture

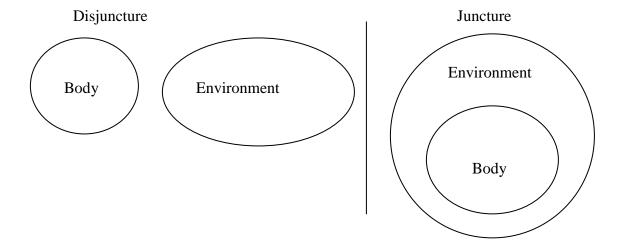


Figure 2 Disjuncture

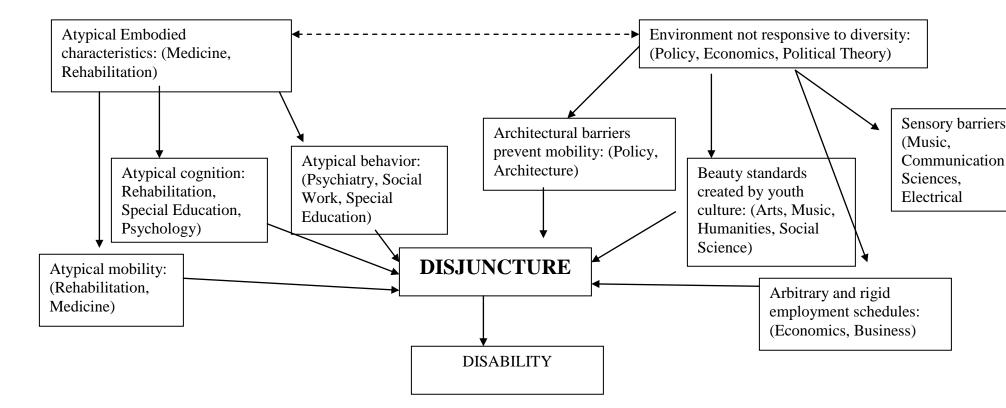


Figure 3 Juncture

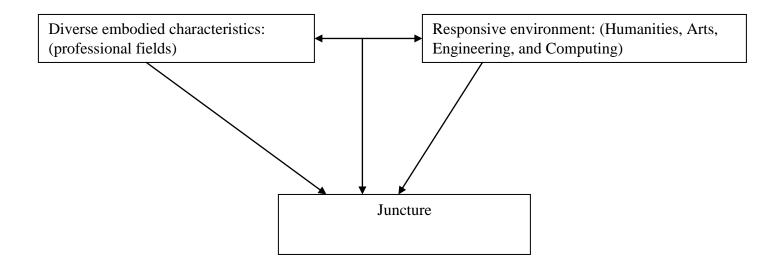


Table 3 Juncture Collaborators

Political theory Economics
Geography Engineering
Medicine Sociology
Business Education
Law Art

Technology Literature
Disability studies Folklore
Computer science Architecture
Philosophy Music

Communications Health, Education and Human

Service Professions

Table 4 Principles for Implementation

- •Rethink disability studies as the fit of bodies and environments
- Promote informed action
- Marry disciplines in a purposive framework
- Broaden the disability studies discourse beyond bodies to purposive and informed thinking and action to advance equality of access and rights
- Locate thinking and action within the mission of universities- to educate students in scholarship and informed action.

Figure 4 Disjuncture Analysis

