

Article

Disability as Microcosm: the Boundaries of the Human Body

Elizabeth DePoy * and Stephen Gilson

Center for Community Inclusion and Disability Studies, University of Maine, 5717 Corbett Hall, Orono, ME 04469, USA

* Author to whom correspondence should be addressed; E-Mail: liz.depoy@umit.maine.edu; Tel.: +1-207-581-1469; Fax: +1-207-581-1231.

Received: 20 August 2012; in revised form: 1 November 2012 / Accepted: 5 November 2012 / Published: 19 November 2012

Abstract: In this paper, we query the legitimacy of the atypical body for membership, quasi-membership, or exclusion from the category of human. Geneticized, branded, and designed as not normal, undesirable, and in need of change, embodied disablement can provide an important but circumvented analysis of the explicit and implicit nature of the legitimate human body, its symbolism, and responses that such bodies elicit from diverse local through global social and cultural entities. Building on and synthesizing historical and current work in the sociology of the body, in disability studies, in cyborg and post-human studies, this paper begins to ask questions about the criteria for human embodiment that are violated by interpretations of disability and then met with a range of responses from body revision to denial of the viability of life. Given the nascent emergence of this important topic, this paper chronicles the theory, questions and experiences that have provoked questions and posited the need for more substantive theory development and verification.

Keywords: humanness; embodiment; disability

1. Introduction

Emerging from an opposition to medical deviance theories of the 20th century, sociology and related disciplines have brought potent intellectual frameworks to an expanded, non-medicalized analysis of disabled bodies. Yet, scholars have only begun to directly engage in interpreting embodied disablement and responses to it as microcosm, meaning, and metaphor for fundamental social, philosophical, and cultural questions about essential elements and boundaries of embodied humanness.

Goffman's classic work [1] briefly addressed the relationship between stigma and humanness or lack thereof, and several scholars such as Gately and Hammer [2] examined symbols of difference as deviance in their analyses. Chandler [3] looked at containing those outside of the boundaries of humanness through institutionalization or other geographic isolation. However a substantive and well-organized literature, which we suggest is a critical but an unmined element of embodiment scholarship to inform action has not yet been initiated.

In this paper, we enter the portal through which to query the legitimacy of the atypical body for membership, quasi-membership, or exclusion from the category of human. Geneticized, branded and designed as not normal, undesirable, and in need of change [4,5], embodied disablement can provide an important but circumvented analysis of the explicit and implicit nature of the legitimate human body, its symbolism, and responses that such bodies elicit from diverse local through global social and cultural entities. Beyond simply theorizing, this dialogue begins to unearth potent and in-depth examination of membership, meaning, and social valuation on the basis of embodied features that exclude bodies from membership of the category of human. Such dialog is essential for clarity and transparency necessary to negotiate and inform eligibility for equality of rights and participation in diverse societies and groups. Building on and synthesizing historical and current work in the sociology of the body, in disability studies, in cyborg and post-human studies within a post-postmodern framework, this paper queries the criteria for human embodiment that are violated by interpretations of interior disability and then met with a range of responses from body revision to denial of the viability of life.

2. Background

"Postmodernism conceived of contemporary culture as a spectacle before which the individual sat powerless, and within which questions of the real were problematized" [6]. Given the post-post-modern aim to move beyond this irony and interpretive elusiveness to thoughtful substance, this paper reflects a post-postmodern trend. While there is not a unitary and agreed upon definition of post-postmodernism, one of its desired outcomes is to counter the postmodern vacuum left by irony and skepticism and thus return substance to thought and action. Also recognizing the global market and technologically advancing context, post-postmodern knowledge relies on dialogue among multiple theoretical, spiritual, aesthetic, and disciplinary arenas as they are brought to bear on both the formulations of and answers to complex questions [6]. Most important for us, is that in opposition to its predecessor, post-postmodernism once again seeks substantive knowledge to inform action, albeit in newly configured "interdisciplines" which competed in the modern scholarly ring and then met with demise in the postmodern carnival.

Within this synthetic approach, a curious matrix of theory and experience emerged and brought us to query the relationship of humanness and disability. Over the years of engaging in the study of disability from multiple disciplinary stances, we, along with many scholars in the field of disability studies, moved from the perspective of disability as contained within the corpus to disability as a broad and complex interaction between corpus and context. Disability is thus seen as an ill-fit, which we refer to as disjuncture [5] between atypical embodied experience and the multiple contexts in which a body acts. More recently, by adopting a post-postmodern approach to querying and seeking knowledge

from diverse scholarship, including theology, philosophy, art, and architecture a note in our own thinking was tweaked. In order to guide informed action to accomplish the goal of healing disjuncture, our gaze needed to be expanded to look at the meaning of the atypical body within the context of defining human desirability and thus humanness.

In this section, we present the theoretical framework and evolution of thinking that forms the bedrock for further organizing an exploration of the interstices of disability and humanness. Humanness in this paper is defined as the attributes that endow an individual with legitimate membership in the category of human and thus entrust that individual with equivalent rights and opportunities, at least ostensibly, that are afforded to other category members.

2.1. Theoretical Framework

Legitimacy theory [5,7] forms the theoretical foundation for this paper. In essence, legitimacy theory leads to questions of what criteria imbue an individual, group, set of ideas, and so forth with authenticity, acceptance, and worth. Embedded within and building on the genre of historical legitimacy theories [8] we chose this theoretical perimeter for its potency in guiding thinking about complex groups, humanness being one of the most contested and multifaceted.

Legitimacy theories can be traced as far back as the writings of Thucydides in 423 BCE, in which questions were posed and answered regarding power, its acquisition, who can morally exercise it, and in what way [8]. Despite legitimacy theory being birthed by political theory, questions of legitimation have been expanded to numerous domains, including but not limited to social norms and rules, distributive justice, and in this paper, to who is a *bona fide* and full member of humanity. And while there are differences in the application of legitimacy theories to diverse substantive questions, what all have in common is their search for credibility and normative acceptance.

The analytic gift brought to this discussion by legitimacy theory is its potential to denude the normative and often unquestioned beliefs and rhetoric about who belongs to a particular group, and then to expose the values that imbue responses to the full continuum of members, quasi-members, and non-members. Thus, given the relative absence of humanness from debates about the nature of disability, legitimacy theory can provide a logical residence to enter and question who is accepted into the home of humanness and who is not.

2.2. Next Thoughts

Framed by legitimacy, questions from several substantive bodies of knowledge coalesced to germinate our curiosity about how embodied disability and humanness intersect, overlap, or diverge. To organize the discussion, Table 1 identifies each arena and the questioning that emerged from it.

In the post-postmodern spirit, we synthesize, amalgamate, and briefly discuss parts of these literatures and the queries that for us arise from them, rather than discussing them as discrete intellectual entities.

Substantive Body of Knowledge	Questioning
Human rights policy	What is the meaning of human? Quasi human?
	Not human? Who is fully, partially or not
	eligible for rights?
Robotics and Human Augmentation	How does technology redefine humanness?
Branding and marketing of "desirable"	How do branding and marketing shape and reify
	common definitions of desirable through
	undesirable humanness?
Art, Architecture, and Curated Display	How do art, architecture and curated display
	shape and reflect common definitions of
	desirable through undesirable humanness?
Embodied conditions—our own and those	How do case exemplars inform the discussion of
in our lives (example of Louise is	humanness?
discussed below)	

 Table 1. Arena and Our Questioning.

2.3. A Quick Glance in the Rear View Mirror

The atypical body presents in numerous forms from the deviant visual through behaviors and thoughts. It is therefore not surprising that multiple paths have been traversed to analyze the scope and nature of the atypical body, the attribution of "disability", and then the meaning of the body in shaping worth and receiving associated responses, from staring [9], to celebration to death [10]. From ancient Greece until current time, a continuum from fascination to revulsion, and ultimately expulsion was enacted in some fashion, whether through symbolism or action. While a full history is way beyond the scope of this paper, the points below provide a conceptual context for the role of the atypical body in establishing markers and parameters for the acceptable to the heinous.

- Within the defective, while specific embodied conditions are treated somewhat differently, most are residents of the "undesirable neighborhood." Some are imprisoned there more than others.
- Responses to people with devalued embodied differences are diverse, engendering a continuum from simple curiosity and disapproving stare [9] through marginalization and being jettisoned from humanness.
- Prior to the Enlightenment, deliberation about humanness took place primarily in philosophy and theology.
- Enlightenment thinking captured the body within a "scientific" bastille, with scientists and professionals taking the lead as humanness sentries.
- Industrialization standardized the desirable body function, size, and appearance.
- Western thinking of the late 20th and early 21st centuries claimed ownership of constructionist viewpoints of discrimination against embodied difference despite their existence throughout history.
- Post-post modernism promises to creatively fill the conceptual void left by postmodern thinkersmarrying previously unfriendly disciplines.

Significant documentation exists in recorded history through current times, whether contained in visual image, illuminated manuscript, philosophical narrative, policy narrative *etc.*, of concern with the embodied atypical [10]. What is considered atypical and where these attributes nudge or rupture the boundaries of humanness differ [11] according to context. But regardless of which condition occupies the atypical seat, social acceptance and how these individuals have been approached are out of the

ordinary. As example, a look back at the history of those who could not hear [12] reveals marginalization until ostensibly, the construct of valued linguistic diversity replaced hearing deficit as a descriptor of the condition of deafness. However, has it really? While the assertion is made that lack of hearing and cognitive function are no longer linked, what about the huge medical and professional industries that seek to remediate barriers to positive learning outcomes joined through "science" to hearing impairment [13]? Synonyms for the term "impairment" include damage, destruction, deterioration, ruination, ruined goods, and wreckage [14] stripping away any obfuscation of negative valuation of the condition of "not hearing" on the part of those who see the biology of hearing as a normative and essential element of full humanness [15].

2.4. Back to Today

Moving from history to contemporary times, we see the ambiguous role of technology, with "human as machine" as one of the major concerns in defining humanness and its non-example [16]. First, the definition of technology in itself is broad and changing. The list that follows below presents five definitions which illustrate technology as knowledge, process, product, and attribute of social groups.

- 1. the branch of knowledge that deals with the creation and use of technical means and their interrelation with life, society, and the environment, drawing upon such subjects as industrial arts, engineering, applied science, and pure science [17].
- 2. the terminology of an art, science, etc.; technical nomenclature. [17].
- 3. a technological process, invention, method, or the like [17].
- 4. the sum of the ways in which social groups provide themselves with the material objects of their civilization [17].
- 5. the making, modification, usage, and knowledge of tools, machines, techniques, crafts, systems, methods of organization, in order to solve a problem, improve a preexisting solution to a problem, achieve a goal or perform a specific function [17].

Diverse perspectives [17–20] span from technology as emancipation and improvement of the organic corpus to the creation of cyborg as the next evolutionary step, decimating the human form [20]. Framed by legitimacy theory, DePoy and Gilson [5] proposed that technology itself is not the direct object on which judgment is formulated, but rather, how technology is designed, acquired, and displayed by the user brands the desirability and humanity of the user and the role of technology as augmenting or detracting from humanness.

In essence, disability, and we would question humanness as well, are not exempt from marketing and branding. According to DePoy and Gilson [5] ascribing labels such as the term "assistive" to technology products functions as a mechanism for extract(ing) users from typical product markets and land(ing) them in disabling social geographies." ([5], p. 89) Moreover, the aesthetic design of products such as medicalized appearing mobility supports is a major branding practice, casting those who need or want such devices as atypical, dependent, and deficient [19]. The question raised by deficit branding leads us to the larger philosophical field of how deficient one must be in order to be considered apart from desirable humanness. Consider the design, implicit appearance, name branding, and difference in

meaning between the hiking stick for all which helps humans recreate (Figure 1) and a cane for the mobility impaired patient displayed in Figure 2.

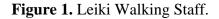




Figure 2. Invacare Bariatric Cane.



More broadly, despite rhetoric to the contrary, abstracts such as specialized rights legislation [22], services, education, specialized programs, and even branded parking spaces serve as identifiers and segregators, removing deficient bodies and then containing, serving them up for observation, and assigning embodied meaning. As example, consider the ascription of person first language only to people sporting designated conditions. This specialized rhetoric was theoretically designed as assertive and celebratory of humanness of individuals previously referred to as diagnostic entities. However, we would suggest that this *trompe l'oiel* is not successful at cloaking the snag in the humanness fabric, resulting from the labeled atypical, as only conditions which are excessively devalued are located after the assertion of "personhood". Contrasting the use of person first language with typical parlance (e.g., person with a disability, but not person with beauty or even person with meanness) can splay open the internally contradictory use of what to us seems like dehumanizing vernacular.

By example as well as non-example, art, architecture, and curated display can both reflect and inscribe the continuum of humanness in bricks and mortar, artist rendering, and installations. Clearly, in the literature and over time, the power of the built environment in communicating meaning has not gone unnoticed. Jencks and Kropf [23] peer way back in the history of humans and divinity referencing the Ten Commandments as the first set of architectural rules which served to admit or reject certain bodies. So over the course of time, spatial, sensory, and virtual architectures have crafted the "human body," sculpting the collective and individual meaning of bodies through the explicit and tacit processes of acceptance or exclusion [10].

Architecture is joined by curated display to create a formal institutional history of the acceptable body. As example, a recent exhibit in the U.S. Smithsonian Museum of Natural History entitled "What Does It Mean to Be Human" invokes an evolutionary history linking humanity to the emergence of the contemporary body. As example, a response about the meaning of "human" showcased on the website is, human is equivalent to "walking, talking, thinking and social being" [24] Further depicting the hegemony of the scientifically correct corpus is "Bodies, The Exhibition" [25]. This traveling global exhibit, by allowing the viewer to inspect the interior corpus, constructs the normal and the abnormal and may be powerful in depicting not human through non-example.

Finally, we get to embodied conditions as heuristic [10] in informing this agenda. Louise, a relative of ours who recently died, acts as exemplar. We depict her later life as reflective of an archetypal intersection of embodied disability and humanness. As her condition, diagnosed as Huntington's disease, became more noticeable, family members moved from descriptive terms of pity to denial of her humanness. Loving relatives whispered, "She would be better off dead", "she is no longer herself", and so forth. When she died last month, common euphemisms such as "now she is at peace" or "her suffering is over" were spoken, despite anyone having conversed with her about the peace or suffering that she may or may not have experienced during her life without and then with Huntington's disease. More profoundly illustrative of dismantling her humanness, any celebration of Louise's life felt absent at her own funeral, as the few in attendance prattled on about their daily lives, not noticing that the purpose of the family gathering was to acknowledge the death of a once beloved family member.

2.5. Navigating the Humanness Field

We now enter and explore the intersection of embodied disability and humanness through the four conceptual but intimate subdivisions that follow and are embedded within the residential property of legitimacy.

Violating humanness: Legitimating the disabled body—what embodied criteria of "humanness" are lost, never obtained, or otherwise not present that assign bodies to the disability category?

Revising the illegitimate—in order to instill or restore humanness, what elements of disabled embodiment are changed and how?

Reinventing embodied humanness—How have bodies been reworked, redesigned, to expand/contract the range of humanness (prosthesis, robotic enhancements, cyborg, avatar)?

Denying humanness: When embodied revision or reinvention cannot occur, what historical and contemporary methods are used to eliminate the violating body (selective aborting, terminating life)?

2.5.1. Violating Humanness

Medical rhetoric is perhaps the most ostentatious, parading values in its discussion of the normal body, the desirable, and the legitimately disabled body. Even before birth, prenatal testing is designed to capture and distinguish the normal from the abnormal and thus can take the position of defining the attributes of humanness that are never obtained by the abnormal. Consider the title of Douglas' book [26], <u>Freedom, Healing for Parents of Disabled Children.</u> This memoir begins with Chapter 1, The Storm, and proceeds with the first narrative sentences, "Something was wrong. I sensed it moments after her birth" ([26], p. 1). Douglas then proposes prayer as the pathway necessary to overcome grief and proceed to more positive configurations of a family living with disappointment and despair. This viewpoint reflects a historical trend of the 20th century for which Olshansky [27] was perhaps best known. This approach posited a developmental grieving sequence enacted upon the birth of a "defective baby".

Throughout the longitudinal process of a life, embodied disability is defined as an impairment resulting from a corporeal anomaly [4]. Diagnosing and labeling a body as legitimately disabled in essence requires that the criteria for desirable development and function **not** be met. Consider the definition of disability posited by the Americans with Disabilities Act and the Equality Act of 2010 in the United Kingdom:

ADA definition: (1) has a physical or mental impairment that substantially limits one or more major life activities; OR (2) has a record of such an impairment; OR (3) is regarded as having such an impairment.

A *physical impairment* is defined by ADA as "any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin, and endocrine."

Equality Act of 2010 definition

A person has a disability if:

- they have a physical or mental impairment
- the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities

Developmental theories structure educational progress, social role, functional, emotive, and other expectations for acceptable human procession from before birth through the end of life. Based on nomothetic methods of inquiry, these theories seek and then define the normal according to what is most frequently observed and then take an axiological turn, assigning value to commonality, defining what "should be" as the minimum standards for human growth and development on the basis of age [10].

Of international reputation as well as debate is the World Health Organization Disability Assessment Schedule (WHODAS 2.0) [28]. This instrument was developed, at least theoretically, as a measure of health and disability without regard to geographic location across the globe. Moreover, the authors claim that the underlying, operationalized construct is disability as interaction among body and environment. It is curious then that the rationale for WHODAS 2.0 links death and disability by urging public health personnel "to move beyond mortality and take into account disability" as a predictor of

what services should be fashioned and delivered to remediate public burden. Moreover, through even a cursory analysis of the 12-item version of the instrument, the definition of disability as embodied and/or functional deficit is logically induced as the measured lexical construct. No assessment of context, environment, or other assertion made in the manual about disability as dynamic and interactive is seen in the instrumentation. The questionnaire measures disability as the extent to which functional "problems" have occurred over a thirty day period resulting from interior embodied health condition, laying out the desirable embodied functions across the globe of upright locomotion, work, hygiene through self care, social interactions, and capacity to concentrate.

In depth analysis of violations as a result of age, appearance, and other embodied functional differences is a scholarly agenda that needs to be fully developed in order to substantively comprehend the interplay of humanness with embodied diversity and difference, and to craft expansive and well informed boundaries for humanness that are not veiled in stereotype, devaluation, and dehumanization resulting from the organic body. However, for now consider the term "developmental disability" as a segue to revising the illegitimate.

As defined by the Developmental Disabilities Act in the United States, developmental disability: means a severe, chronic disability of an individual 5 years of age or older that:

- 1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- 2. Is manifested before the individual attains age 22;
- 3. Is likely to continue indefinitely;
- 4. Results in substantial functional limitations in three or more of the following areas of major life activity;
 - (i) Self-care;
 - (ii) Receptive and expressive language;
 - (iii) Learning;
 - (iv) Mobility;
 - (v) Self-direction;
 - (vi) Capacity for independent living; and
 - (vii) Economic self-sufficiency.
- 5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such a term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

This characterization both divulges violations to humanness and moves us to a discussion of what is necessary for revision of the illegitimate.

2.5.2. Revising the Illegitimate

Before we begin this section, we clarify it exclusively as questioning about revising illegitimate bodies rather than our determination of the value or lack thereof of any services or professional activity. We assert that in order to be precise in posing queries, complexity needs to be parsed and reduced such that the object of analysis is clear and logical, and focused dialog can occur without being interspersed with related but tangential opinion. So this discussion does not prescribe action, but rather focuses its gaze on querying the body as microcosm and meaning.

So let us begin this section with item #5 in the Developmental Disabilities Act (DD Act). As displayed above, this item remands those with developmental violations to a lifelong system of interventions. In a recent presentation given by graduates of an early intervention master's degree program, well-intended students reflected the DD Act policy, essentially capturing violating children in a lifelong service system for the purpose of ongoing revision towards the developmental norm. It was even more curious to note that comments from the audience affirmed the need for such segregated services, espousing the grand narrative of the inhumanity of the disabled bodies of their children. In the presentation context, terms such as "typically developing" and "atypically developing" masquerade as euphemisms for normal and abnormal child growth and development respectively. Legitimated membership in these service systems affirms the assertion of the need for permanent and regular help in order to achieve or even approximate developmentally theorized and desired human milestones, maintaining dependence beyond what is valued within the scope of developmental theories.

Genetic counseling and parent training are exemplary of revision strategies as well. Lurking in these services is the *a priori* and essentialist assumption of violation of the offending body and the universal need for extraordinary and prescriptive, professionally guided interactions between parents and their children.

Selective genetic and surgical manipulation of impaired fetuses and bodies further shine the spotlight on measures taken to revise bodies towards the norm. As example, revision of atypical gait is common for bodies who move through space in illegitimate manners despite their mobile functionality [29].

Among the many strategies revealing desired revisions for violating adult bodies are vocational rehabilitation, plastic surgery, and assistive technology. We use assistive technology as exemplar and segue into reinvention in this paper and leave a discussion of the meaning of services and medical interventions for violating bodies to a future analysis.

"Assistive technology" is technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible [30]. We would suggest that the term assistive is another contemporary euphemism for segregation and prescription on the part of well-intended providers. Under the banner of "assistive", devices estimate theoretical constructs of developmentally appropriate humanness only for members of the embodied disability category. As example, memory and communication aids are prescribed for youth and adults referred to specialist providers because of eligible diagnostic conditions. However, we would challenge and thus name assistive technology as constructed, resulting in ongoing labeling, devaluation, and segregation of the violating body. Why is a mobile or tablet-based calendar an assistive memory device for diagnosed bodies and simply an app for others? Doesn't technology allow all people to accomplish what they could not do without it? As example, in a perusal of Enablemart.com [31], commercially available products such Glow Dome, a toy that won the 2009 Good Housekeeping Best Toy Award, text to speech software, portable folding computer keyboards, and Bluetooth head sets among many other items were identified as assistive technology, fattening the profits for the disability industry at the symbolic expense of subjected atypical bodies. Yet these products are used by all bodies, regardless of embodied label.

2.5.3. Reinventing Embodied Humanness

As we noted above, technology is an important and central link between embodied revision and reinvention. Recent work in two areas of technology research and development and related teaching, movement-inspired robotic devices, and avatar communication, led us to the literature on cyborg studies and post-humanism [20,32] querying the acceptable boundaries of the human corpus. Debates about the extent to which exogenous paraphernalia diminish or augment humanness abound. As example Case [33] suggests that all people in the contemporary world are both cyborgs and more human as result of digital networking and devices. An excellent summary of opposition to technology as supportive of humanness was posited by Kelly [21]. He identified the major arguments against the technological reinvention of violating bodies as related to the unnatural and non-spiritual attributes of technological enhancement. The range of perspectives was captured in the recent London Olympics by the debates regarding the participation of Oscar Pistorius. Reinforcing his participation despite his reliance on prosthetic lower extremities is the position that he has no advantage as a result of non-organic body enhancements. To the contrary are those who claim that he is different, advantaged, and thus "superhuman" because of his use of prosthetics. Further confusing the legitimacy of reinvention is a study by Weyland et al. [34] in which their analysis "conclude(d) that running on modern, lower-limb sprinting prostheses appears to be physiologically similar but mechanically different from running with intact limbs" ([34], p. 903).

The legitimacy of reinvention for eligibility as conceptually and desirably human remains at question, but unlike the next part of this discussion, is not a matter of lethal concern. We turn now to that arena.

2.5.4. Denying Humanness

Each year in our course on introduction to disability studies we discuss historical practices aimed at embodied difference. As noted above, over the longitude of documented human existence, embodied difference has made its regular appearance. Definition of the atypical body was and is context dependent, and although not always the case, those whose fortune was to display embodied difference often met with marginalization through elimination with those at the extremes engendering the most severe consequences of denying humanness [5,35–37]. Until the students in the class encounter an analysis of current denials of humanness, they bristle at historical practices such as leaving atypical infants to die, institutionalizing those with unacceptable behavior, and showcasing children with mobility impairments on telethons.

As we indicate to our students, before we delve into exemplars of current denial strategies, we once again clarify that we do not argue for the ethical or moral correctness of each. Once again, complexity that inheres in such analyses requires a careful dissection and focus on parts of a phenomenon. As example, our discussion of selective abortion does not address the issue of the right to choose, but instead illuminates the role of these policies and practices in bringing to light questions regarding the boundaries that are permeated by embodied disablement. Although contested for internal inconsistency and moral position [38] opponents of selective abortion on the basis of disability discrimination identify its eugenic aim. That is to say, specific embodied conditions are denied as worthy of human life and thus eliminated before birth. The imperative to identify and terminate life for undesirable conditions has been indicted with negative implications as well for those who made it past birth [39]. This practice once dissected for the students moderates their disdain for previous civilizations.

A similar argument has been made for physician-assisted suicide. Once again, we are not taking a moral position on the right to die, who should decide, assist, and so forth. Rather we include this discussion as an illustration of how the violating body, which cannot be revised or reinvented, captures contextual values and conflicts and provides a rich opportunity for analysis.

Singling out violating bodies for such assistance has been analogized to genocide [40]. This practice has a long history in multiple geographies. What seems to underpin the acceptance or rejection of any type of euthanasia is the valuation placed on both the construct of human life in itself and individual lives meeting the criteria for human worth. So the acceptability of voluntary death, aided or unaided, peeks into the axiological soul of a culture, allowing leakage of values and ethics to the public. While assisted or voluntary death was in essence an active process prior to the ascendency of contemporary medical intervention, medical practices such as medications, resuscitation, and surgeries to prolong life introduced a more convoluted moral decision morass. As example, the classic 1915 case in which Haiselden, a physician, chose not to operate on a neonate with a severe "deformity" created an ethical maelstrom by raising the duty of professional withholding as well as direct administration of a lethal agent as a means to end life. Look at the following argument about the viability of assisted suicide and related voluntary death practices:

Fear, bias, and prejudice against disability play a significant role in assisted suicide. Who ends up using assisted suicide? Supporters advocate its legalization by suggesting that it is needed for unrelievable pain and discomfort at the end of life. But the overwhelming majority of the people in Oregon who have reportedly used that state's assisted suicide law wanted to die not because of pain, but for reasons associated with disability, including the loss of autonomy (89.9 percent), the loss of the ability to engage in activities that make life enjoyable (87.4 percent), the loss of dignity (83.8 percent), and the loss of control of bodily functions (58.7 percent). Furthermore, in the Netherlands, more than half the physicians surveyed say the main reason given by patients for seeking death is "loss of dignity" [41].

Before we depart from this topical area, we briefly raise more abstract harbingers that may divulge denial of humanness, wrongful birth and wrongful life policies. Unpacking such controversial policy and practice juxtaposes humanness, economics, jurisprudence, and more profoundly axiology and ontology to raise questions about the perimeters of human and who guards them, violates them, and then is responsible for the emotive and fiscal costs of living as a denied human.

Both wrongful birth and life policies assert that the life of a defective child is so heinous that he/she should not be alive [42]. The distinction lies in who brings the legal claim against whom. In wrongful birth, the parent initiates action against the physician for providing insufficient information on which to make an informed decision based on predicted quality or lack thereof of human life, while in wrongful life, the child or child advocate is the plaintiff [43].

So, while the subjects of these actions are alive, the formal, legal denial of their humanness is inscribed in policies that allow for punitive action and recovery of monetary damages for failing to prevent a denied life from occurring.

3. Conclusions

As is evident in the cross-disciplinary foundation, conceptual framework, and multiple exemplars above, the relationship between disabled embodiment and legitimacy of humanness provides a scholarly multiplex yet to be developed and applied to equality and respect. We would suggest that analysis of the disabled body as microcosm continues to be concealed in underexplored intellectual territory. As such, terms such as human rights, citizenship, human responsibility, triage, and so forth remain vague as well. The role of the atypical embodied can be potent in clarifying conceptualizations, conflicts, and negotiations of the boundaries of humanness such that it should not be overlooked in socially responsible thought and action. Because of the nascence of explicit theory of the interstices of the embodied atypical and humanness, this paper provides no answers or action agendas. Rather, our intent was to illustrate the convoluted but intellectually rich pathways necessary to develop this field of investigation as the basis for reflection and informed action.

References and Notes

- 1. Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*; Prentice Hall: Englwood Cliffs, NJ, USA, 1963.
- Gately, S.; Hammer, C. A textual deconstruction of rudolph the red—nosed reindeer: Utilitarian, mechanistic, and static constructions of disability in society and in schools. *Essays Philos.* 2008, 9, Article 9. Available on line: http://commons.pacificu.edu/eip/vol9/iss1/9/ (accessed on 21 June 2011).
- 3. Chandler, D. Semiotics: The Basics; Routledge: New York, NY, USA, 2004.
- 4. Gedge, E. Genetics, disability and symbolic harm. In *Illness, Bodies and Contexts*, Lange, I.N., Norridge, Z., Eds.; Inter-disiplinary Press: Oxfordshire, UK, 2010.
- 5. DePoy, E.; Gilson, S.F. Studying Disability; Sage: Thousand Oaks, CA, USA, 2011.
- Post-Postmodernism. Available online: http://www.scribd.com/doc/5710598/Post-Post-Modernism (accessed on 4 August 2012).
- 7. DePoy, E.; Gilson, S.F. *Rethinking Disability: Principles for Professional and Social Change*; Brooks-Cole: Pacific Grove, CA, USA, 2004.
- 8. Zelditch, M. Theories of legitimacy. In *Psychology of Legitimacy*, Jost, J.M., Ed.; Cambridge University Prss: New York, NY, USA, 2001; pp. 33–35.
- 9. Garland-Thomson, R. Staring: How We Look; Oxford University Press: New York, NY, USA, 2009.
- 10. DePoy, E.; Gilson, S.F. *Human Behavior Theory and Applications: A critical Thinking Approach*; Sage: Thousand Oaks, CA, USA, 2012.
- 11. Hayry, M. *Rationality and the Genetic Challenge*; Cambridge University Press: Cambridge, UK, 2010.
- 12. Nomeland, M.; Nomeland, R. *The Deaf Community in American: History in the Making*; McFarland & Company: Jefferson, NC, USA, 2012.

- 13. Marschark, M.; Hauser, P. *Deaf Cognition: Foundations and Outcomes*; Oxford: New York, NY, USA, 2008.
- 14. Dictionary.Com. Technology. Available online: http://dictionary.reference.com/browse/ technology?s=t (accessed on 3 August 2012).
- 15. Seikel, J.A.; King, D.; Drumright, D.G. *Anatomy & Physiology for Speech, Language, and Hearing*; Delmar Cengage Clifton Park, NH, USA, 2009.
- 16. Muri, A. *The Enlightenment Cyborg: A History of Communications and Control in the Human Machine, 1660–1830*; University of Toronto Press: Toronto, Canada, 2007.
- 17. Wikipedia. Technology. Available online: http://en.wikipedia.org/wiki/Technology (accessed on 3 August 2012).
- 18. Wolfe, C. What is Posthumanism? University of Minnesota: Minneapolis, MN, 2010.
- 19. DePoy, E.; Gilson, S.F. *Branding and Designing Disability*; Routledge: Abingdon, Oxon, UK, in press.
- 20. Haraway, D. Situated Knowledges in Simians, Cyborgs, and Women; Routledge: New York, NY, USA, 1991.
- 21 Kelly, K. 4 arguments against technology. Available online: http://blogs.hbr.org/now-new-next/2009/04/4-arguments-against-technology.html (accessed on 11 August 2012).
- 22. Bagenstos, S. *Law: The Contradictions of the Disability Rights Movement*; Yale University Press: New Haven, CN, USA, 2009.
- 23. Jencks, C.; Kropf, K. *Theories and Manifestoes of Contemporary Architecture*, 2nd ed.; John Wiley & Sons: Hoboken, NJ, USA, 2006.
- 24. What does it mean to be human? Available online: http://humanorigins.si.edu/about/involvement/ being-human (accessed on 2 August 2012).
- 25. Premier Exhibitions.Bodies: The exhibition celebrate the wonder of the human form. Available online: http://www.bodiestheexhibition.com/ (accessed on 10 July 2012).
- 26. Douglas, N. *Freedom: Healing for Parents of Disabled Children*; Olive Leaf Ministries: Kansas City, MO, US, 2008.
- 27. Olshansky, S. Chronic sorrow: A response to having a mentally defective child. *J. Soc. Casework* **1962**, *43*, 190–193.
- 28. Ustün, T.B.; Kostanjsek, N.; Chatterji, S.; Rehm, J. World health organization disability assessment schedule ii (whodas ii). Available online: http://www.who.int/icidh/whodas/index. html (accessed on 20 July 2012).
- Saraph, V.; Zwick, E.B.; Auner, C.; Schneider, F.; Steinwender, G.; Linhart, W. Gait improvement surgery in diplegic children: How long do the improvements last? *J. Pediatr. Orthop.* 2005, 25, 263–267.
- University of Washington. AccessIT. Available online: http://www.washington.edu/accessit/ (accessed on July 31, 2012).
- 31. Glow dome. Available online: http://www.enablemart.com/Catalog/Arts-Crafts/Glow-Dome (accessed on 15 July 2012).
- 32. Kurtzweil, R. The Singularity is Near; Penguin: New York, NY, USA, 2006.
- 33. Amber Case: We are all cyborgs now. Available online: http://www.ted.com/talks/amber_case_ we_are_all_cyborgs_now.html (accessed on 1 August 2012).

- Weyand, P.G.; Bundle, M.W.; McGowan, C.P.; Grabowski, A.; Brown, M.B.; Kram, R.; Herr, H. The fastest runner on artificial legs: Different limbs, similar function? *J. Appl. Physiol.* 2009, 107, 903–911.
- 35. Rispler-Chiam, V. Disability in Islamic Law; Springer: Dordrecht, The Netherland, 2007.
- 36. Nakamura, K. *Deaf in Japan: Signing and the Politics of Identity*; Cornell University Press: Ithaca, NY, USA, 2006; p 226.
- 37. Metzler, I. Disability in Medieval Europe: Thinking about Physical Impairment in the High Middle Ages, c.1100–c.1400; Routledge: New York, NY, USA, 2006.
- 38. Lange, I.; Norridge, Z. Illness, Bodies and Contexts; Inter-disciplinary Press: Oxford, UK, 2010.
- 39. Flanders, N. Sex selection abortions shock us, but abortion of the disabled still justified. Live Action Blog Available on-line: http://liveaction.org/blog/sex-selection-abortions-shock-us-but-abortion-of-the-disabled-still-justified/. (Accessed on 2 August 2012).
- 40. Coleman, D. Assisted suicide laws create discriminatory double standard for who gets suicide prevention and who gets suicide assistance: Not dead yet responds to autonomy, inc. *Disabil. Health J.* **2010**, *20*, 39–50.
- 41. Disability Rights and Education Fund Why assisted suicide must not be legalized. Available online: http://www.dredf.org/assisted_suicide/97-DREDF-website-version.html (accessed on 1 August, 2012)
- 42. Rimon-Zarfaty, N.; Rax, A. Abortion committees as agents of eugenics: Medical and public views on selective abortion following mild or likely fetal pathology. In *Community: Reproductive Technologies among Jewish Israelis*, Kin, G., Ed.; Berghahn Books: New York, NY, USA, 2012; pp. 202–225.
- 43. Wolbring, G. Wrongful birth/life suits. Available online: http://www.bioethicsanddisability.org/ wrongfulbirth.html (accessed on 1 August 2012).

© 2012 by the authors; licensee MDPI, Basel, Switzerland. This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution license (http://creativecommons.org/licenses/by/3.0/).