

## **The Ethics of Making Space for Non-Conformist Minds and Bodies in Healthcare**

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*This paper investigates the place of the disabled body in health care provision. Increasingly, differences in cognition and physicality are being re-framed and mediated in terms of social value. Disabled people have had little input in developing the space in which we find ourselves at present. We examine various historical, cultural and social perceptions underlying this debate.*

### **Background and Context**

Health and disability are often perceived and defined as binary opposites. That is, "health" is often simply defined as the absence of disability. Moreover, the concept of "health promotion" may be perceived, in some contexts, as the modern eugenics, a new threat to disability in public space. Attitudes concerning health and disability are potentially being reconfigured by technological "advances" practiced in specific places. Disabled people encounter the spaces of health care as they are now changing, mediated by new determinants. Thus, we are faced with functioning states that may choose to no longer provide space for what some perceive as "failed" minds and bodies (Mostert, 2002). This process is not benign; certain notions of the body and mind underscore the debate (Bailey, 1996; Corker & Shakespeare, 2002). Ethicist Peter Singer (1994) proposes "to embrace a social ethic where some human lives are valued and others are not" (Singer, 1994, p.121). Burleigh (1997) documents an increasingly unsophisticated approach to

life. This is reflected in Nussbaum (2006), who speaks of an “ethically evaluative” process whereby:

[W]e seek a higher threshold, the level above which not just mere human life, but good life, becomes possible. (p. 181)

The perceptions and opinions of disabled people are rarely given space in these debates (Wolbring, 2002). As a society, we have yet to develop a comfort level with the “messiness” that constitutes humanity. There is often a tendency to conflate “quality of life” with worthiness to live.

Community membership space, or the state of belonging or not, to communities, may be determined, in part, by socially defined identifiers of acceptable physicality or intellect. Socially-ascribed markers determine degrees or levels of inclusion, and the presence of disability seems to challenge the accepted markers of humanity or normalcy. Social assumptions, including reactions to perceived differences, appear to harken back to ancient belief systems ingrained deep within the collective social consciousness. (Hansen, 2002).

Increasingly, the complexity and diversity of humanity are framed as a series of “problems” to be dealt with (Kerr & Shakespeare, 2002). The perspective presented in the mainstream is often oversimplified (Kerr & Shakespeare). The rationality of science provides the impression of impartiality and equilibrium (Kerr & Shakespeare). However, past practice and strongly ingrained social beliefs may have a profound impact on the development focus and direction of research (Mostert, 2002) One is constantly amazed and appalled by the fact that disabled people are repeatedly absent, silenced, and depicted in stilted, primitive simplicity in much of what purports to be disability research (Hansen, 2002).

Human beings are far more complex than our genetic make-up (Kerr & Shakespeare, 2002). A better understanding of the elements of disability in manifested in daily life and the interconnections between the

corporeal, cognitive, and social realities which accompany disabling conditions provides a more complete picture of disability reality with respect to people's health care. Time, space and speed elements as well as dominant social attitudes need to be factored into the access equation. Looking at issues such as information communication and access to plain language information is pivotal. Access to sign language interpretation and information in non-print materials is key for people who are deaf or do not use spoken language to communicate.

Disabled people should have access to the same level and choice of health care services as people without disabilities. Gleeson's (1999) work on historical materialism acknowledges that certain forms of physicality and intellect acquire social franchise.

Disabled people are often viewed as being out of place. The "able" body is the "natural" way of being. Hence, society has yet to develop a "comfort level" with so-called "messy" or "leaky" bodies.

The body is never a single physical thing so much as a series of attitudes toward it. (Davis, 2002, p. 22)

The boundaries between the community, the individual and the body are fluid although they are often presented as fixed and unchanging (Tremain, 2002). Yet, disability or impairment and ability are often presented as opposites although they exist simultaneously on the same plain (Michalko, 2002). The lived experience of disability is rarely expressed from the centre, but rather from the margins (Michalko, 2002). Knowledge from the margins is perceived as "defective," not usually worthy, credible or useful (Michalko, 2002). "Recognized" knowledge is located in the non-disabled sphere (Michalko, 2002).

Medical authority has a profound influence in disabled people's lives (Begum, 1996a). Everything from disabled parking permits to tax credit eligibility requires a medical assessment. A medical diagnosis is usually required to obtain access privileges to essential programmes that are supposed to facilitate and maintain independence within the mainstream community. Physicians are, thus, in many ways, "gatekeepers" to the

broader social mainstream (Titchkosky, 2002). However, accommodation of disability issues has not been a priority for most medical professionals. A lack of information or awareness of disabilities can create greater (at times life threatening) difficulties for the people seeking information concerning changes in their medical condition. Medical professionals are not immune to the widely held perceptions concerning disability and impairment (Begum, 1996b).

The Practitioner's response is often based on what s/he believes to be the ability and competence of the disabled person based on his/her functional impairment, rather than on a recognition of how external factors, such as access to the right equipment, or how the availability of sign language interpreters might adversely affect perceptions of competence (Begum, 1996b).

### **The Body: re-framing**

Society often subjectively defines certain characteristics as valuable, while others are to be avoided or eliminated (Young, 1997). Gesler and Kearns (2002) explain how this subjective process is used to validate differential treatment:

The strategy often used in constructing cultural difference is to naturalize it or make it appear as though it is only natural, the way of the world, an understood truth, not subject to question. Naturalization serves also to legitimise a system of difference.

(Gesler & Kearns, 2002, p. 99)

Western society arbitrarily imposes fixed bodily expectations on its members (Morris, 1991). Acceptable shape, size, colour, height, sexuality, physicality and intellect are all culturally mediated (Butler, 1990; Young, 1997):

Concepts of race, gender and class shape the lives of those who are not black, poor or female, so disability regulates the bodies of those who are "normal." The

concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability. Normalcy and disability are part of the same system (Davis, 1995). Medical science mirrors the cultural norm and “profoundly shapes our assumptions about what a normal body is ...” (Leach Scully, 2002, p. 53).

The ideology of eugenics haunts the discourse of average capacity of the body as machine in an industrial society (Hahn, 1989). Perfection is equated with uniformity and the norm (Davis, 1995, Morris, 1997), and disability is equated with the non-standard deviant population (Davis, 1995; Hahn, 1989). Fear of difference is arguably the underlying rationale, although it is rarely articulated as such (Baird, 1992; Young, 1997).

### **Knowledge and Power**

Science objectifies and dominates much of the discussion about disability (Young, 1997), while assumptions about the static nature of disability and impairment permeate the discourse (McDowell, 1999). Many disabled people and their allies have a detailed knowledge and an understanding of their impairments drawn from daily life experience. Yet, many people relate instances where this knowledge was questioned or dismissed when seeking medical treatment (Hansen, 2003).

Disabled people often obtain primary care in hospitals. For most of these people, the experience was not a positive one, owing to the largely inflexible nature of the hospital setting (Hansen, 2003). They felt the need to take proactive measures in order to prevent their health status from being compromised:

There’s times when you’re an in-patient in the hospital and maybe none of the people who really know you well are around and sometimes that can feel ... you

don't understand what I'm telling you 'I insist really that I have my PAs.[personal assistants]. with me in hospital from when I wake up to when I settle down for the night. And that's exceedingly helpful because if I didn't have them I would feel very exposed in hospital. Some[hospital staff] don't have the understanding. Some don't have enough staff, And sometimes the structure just makes health care delivery ..quite difficult. (Rainbow, 46, Edinburgh) (Hansen, 2003, p. 20)

At the hospital ... I just don't, don't feel listened to at all, 'cause I just feel as though I don't matter to them, and, the impact of ... changes in my visual impairment, they don't take that on at all. And they never, like they don't offer any information ... they don't offer any information like, in terms of, counselling services or, benefits, or anything like that, ... a lot of that I've had to find out for myself over the years. (Jennifer, 37, Stirling) (Ibid.)

Cultural understandings provide the framework by which ethical understandings are introduced and interpreted (Kerr & Shakespeare, 2002). In many ways, the determinist view of disability reflects elements of the medical model. Increasingly, we as a society are pressured into compliance with majority understandings of disability construed as "progress" (Kerr & Shakespeare). Failure to do so runs the risk of some form of social sanction, and this perspective is rarely if ever subjected to critique.

Because both cultural and ethical understandings of disability are generally grounded in the medical model of disability, they can offer, at best, only a one-dimensional, deficit-based approach to ethical issues related to disability. Traditional health ethics examines "quality of life" in relation to disability in terms of the effects of an impairment on an individual's relationship to the environment, but a disability-ethics perspective requires us to also examine the effects of marginalization on the individual, and the effects of stigma on the social perception of the

individual's quality of life. Thus, while traditional health ethics tends to evaluate an individual's quality of life in the presence of disability in terms of social function, a disability-ethics perspective calls us to consider the impact that an individual's social worth has on his/her "quality of life." So, while a traditional Medical/Bioethics perspective prompts us to ask questions like: "Would the greater good be best served by allocating limited resources to facilitate the continued inclusion/life of a single person with disabilities, or to promote the continued well-being of a far larger number of people without disabilities?", a Disability-Ethics perspective prompts us to ask questions like: "What are the commonly-held values that will cause a society to either include or exclude disabled people?" and, "What sorts of assumptions and/or knowledge about the experience of disability underpin these commonly-held values?" These are precisely the sorts of questions which identify and expose the dangers to vulnerable populations, including people with disabilities, which are inherent in many emerging policies surrounding medical treatment at end-of-life, such as the policy of Withholding and Withdrawing Treatment.

The policy of Withholding and Withdrawing Treatment, as it is commonly conceptualized by the medical authorities seeking its implementation, is based on the notion that there should be a "minimum goal of treatment," and that patients who fail to meet the criteria for this "minimum goal of treatment" should no longer be considered eligible for "life-sustaining treatment." One of the most fundamental—and potentially most dangerous—problems with the medical concept of a "minimum goal of treatment" as it pertains to the debate around withholding and withdrawing treatment is that it is generally defined solely in terms of a traditional Medical/Bioethics perspective, and thus leaves no room for the kinds of considerations that a Disability-Ethics perspective calls us to examine and to take into account. In other words, there may be many cases in which the presence of a pre-existing disability automatically makes it impossible for individuals to meet the criteria of the medical/bioethical concept of a "minimum goal of treatment" because they were in fact living in a condition that fell short of the "minimum goal of treatment" even before their medical condition became acute or critical. Common examples of this type of scenario

include the routine use of respirators by individuals who have Post-Polio Syndrome, and the routine use of a PEG tube by people with Cerebral Palsy and other neurological disorders as a means of eating and drinking. Clearly, in these sorts of situations, conventional Medical/Bioethical understandings of concepts such as “artificial nutrition/hydration,” “extraordinary measures,” and “futility of treatment” become highly problematized, when examined from a Disability Ethics perspective.

Another contemporary, and rather frightening, example of the way in which the presence of a pre-existing disability problematizes the conventional Medical/Bioethical concept of a “minimum goal of treatment” is seen in the recently released “Triage Protocol for Critical Care During an Influenza Pandemic.” Published in the Canadian Medical Association Journal, this protocol sets out a prioritization hierarchy for determining patient eligibility for receiving critical care, specifically the use of ventilators, in the event of an influenza pandemic and the resulting catastrophic overloading of critical care units. This Protocol sets forth the following criteria for determining whether or not individual patients should receive critical care during an influenza pandemic:

#### **Inclusion criteria**

The patient must have 1 of the following:

*A. Requirement for invasive ventilatory support*

- Refractory hypoxemia (SpO<sub>2</sub> < 90% on non-rebreather mask or FIO<sub>2</sub> > 0.85)
- Respiratory acidosis (pH < 7.2)
- Clinical evidence of impending respiratory failure
- Inability to protect or maintain airway

*B. Hypotension* (systolic blood pressure < 90 mm Hg or



relative hypotension) with clinical evidence of shock  
(altered level of consciousness, decreased urine output or other evidence of end-organ failure)  
refractory to volume resuscitation requiring vasopressor or inotrope support that cannot be managed in ward setting

### **Exclusion criteria**

The patient is excluded from admission or transfer to critical care if any of the following is present:

*A. Severe trauma*

*B. Severe burns of patient with any 2 of the following:*

- Age > 60 yr
- > 40% of total body surface area affected
- Inhalation injury

*C. Cardiac arrest*

- Unwitnessed cardiac arrest
- Witnessed cardiac arrest, not responsive to electrical therapy (defibrillation or pacing)
- Recurrent cardiac arrest

*D. Severe baseline cognitive impairment*

*E. Advanced untreatable neuromuscular disease*

*F. Metastatic malignant disease*

G. *Advanced and irreversible immunocompromise*

H. *Severe and irreversible neurologic event or condition*

I. *End-stage organ failure meeting the following criteria:*

*Heart*

- NYHA class III or IV heart failure

*Lungs*

- COPD with FEV1 < 25% predicted, baseline PaO<sub>2</sub> < 55 mm Hg, or secondary pulmonary hypertension
- Cystic fibrosis with postbronchodilator FEV1 < 30% or baseline PaO<sub>2</sub> < 55 mm Hg
- Pulmonary fibrosis with VC or TLC < 60% predicted, baseline PaO<sub>2</sub> < 55 mm Hg, or secondary pulmonary hypertension
- Primary pulmonary hypertension with NYHA class III or IV heart failure, right arterial pressure > 10 mm Hg, or mean pulmonary arterial pressure > 50 mm Hg

*Liver*

- Child-Pugh score <sup>3</sup> 7

J. *Age > 85 yr*

*K. Elective palliative surgery*

*Note: SpO<sub>2</sub> = oxygen saturation measured by pulse oximetry, FIO<sub>2</sub> = fraction of inspired oxygen, NYHA = New York Heart Association, COPD = chronic obstructive pulmonary disease, FEV<sub>1</sub> = forced expiratory volume in 1 second, PaO<sub>2</sub> = partial pressure of arterial oxygen, VC = vital capacity, TLC = total lung capacity.*

(Christian, M. D. et al 2006: 1379)

The authors of this Protocol assure us that “When resource scarcities occur, the tenets of biomedical ethics and international law dictate that triage protocols be used to guide resource allocation ... We have developed this triage protocol in an effort to ensure the equitable and efficient use of critical care resources if scarcities occur during an influenza pandemic.”

Yet, even in spite of such apparent ethical surety, we do not think it an overstatement to say that this Protocol blatantly ignores the fundamental human rights of people with disabilities. Again, we think it is important to stress the limited purview of this protocol, as it really only addresses the issue of which patients would be eligible to receive treatment with respirators in the event of an influenza pandemic. Practically speaking, only a fractional percentage of patients would in fact either require or benefit from treatment with a respirator in such a situation anyway. Having said that, however, we still find some of the criteria set forth in this Protocol for the withholding of treatment extremely problematic, when viewed from a Disability Ethics perspective. For example, in identifying a “Severe and irreversible neurologic event or condition” or a “Severe baseline cognitive impairment” as criteria for the withholding of treatment, this Protocol in effect excludes virtually all people with pre-existing physical and/or developmental disabilities from treatment. The potential for this kind of exclusionary, ability-based treatment protocol to be adapted and transferred over to other areas of medical practice poses a very real, and—as many would argue in the wake of the

Golubchuk case—a very present danger to vulnerable Canadians. It highlights the urgent need for the articulation and integration of a Disability Ethics perspective into the practices of Medicine and Bioethics.

### **Conclusions**

Thus, in the 21st Century, we, as disabled people, are often faced with an interesting paradox. We have acquired more social acceptance than ever before as numerous pieces of rights legislation attest (Mostert, 2002). Yet, at the same time, disabled people and their allies are regularly placed in a situation of having to justify access to treatment and the right to live on the basis of individual economic and social utility at either end of the life continuum (Mostert, 2002).

Health service professionals and the disability rights movement can together play an important role in moving away from the potentially deadly perfect body syndrome. Deeply-held notions about what comprises the “disabled” body require critical and creative analysis outside of the narrow objectifying boundaries of science. The traditional, exclusionary authority of medical science cries out for critical mediation through a paradigm shift which incorporates a new set of perspectives beyond the overreaching normative which has gone before. Above all, the disability/pathology dualism must be abandoned in favour of a model that values and respects bodily difference (Thomson, 1997); physicality should not be the sole determinate of an individual’s worth (Lisi, 1993). Technological developments are having a profound impact on the lives of disabled persons, both in terms of service access and delivery (Mostert, 2002). We must begin to examine medical ethics in the context through which it has developed, recognizing that it is framed by market forces that are driven by social and cultural subjectivities (Kerr & Shakespeare, 2002). The development and application of a disability ethics framework thus offers an opportunity to affect the kind of paradigm shift that is necessary to make healthcare truly inclusive of people with disabilities.

## References

- Bailey, R. (1996). Prenatal testing and the prevention of impairment: A woman's right to choose. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability* (pp. 143-167). London: Women's Press.
- Baird, V. (1992). Difference and defiance. *The New Internationalist*, 233 (July), 4-7.
- Begum, N. (1996a). Disabled women's experience of general practitioners. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability* (pp. 168-193). London: Women's Press.
- Begum, N. (1996b). The general practitioners' role in shaping disabled women's lives. In C. Barnes & G. Mercer (Eds.), *Exploring the Great Divide* (pp. 157-172). Leeds: Disability Press.
- Burleigh, M. (1997). *Ethics and extermination: Reflections on Nazi genocide*. Cambridge: Cambridge University Press.
- Butler, J. (1990). *Gender trouble: Feminism and the subversion of identity*. London: Routledge.
- Christian, M. D., Hawryluck, L., Wax, R. S., Cook, T., Lazar, N. M., Herridge, M. S., et al. (2006). Development of a triage protocol for critical care during an influenza pandemic. *CMAJ*, 175(11), 1377-1381.
- Corker, M., & Shakespeare, T. (2002). Mapping the terrain. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity embodying Disability Theory* (pp. 1-17). London: Continuum.
- Davis, L. (1995). *Enforcing normalcy: Disability, deafness and the body*. New York: Verso.
- Davis, L. (2002). *Bending over backwards: Disability, Dismodernism and other difficult positions*. New York: NYU Press.
- Gesler, W., & Kearns, R. (2002). *Culture/place/health*. London: Routledge.
- Gleeson, B. (1999). *Geographies of Disability*. London: Routledge.
- Hahn, H. (1989). Disability and the reproduction of bodily images: The dynamics of human appearances. In J. Wolch & M. Dear (Eds.), *The power of geography: How territory shapes social life* (pp. 370-388). London: Unwin Hyman.

- Hansen, N. (2002). *'Passing' through other peoples' spaces: Disabled women geography, and work*. Unpublished PhD. Thesis, University of Glasgow, Glasgow, Scotland.
- Hansen, N. (2003). *Health care settings and sites: Making a place and space for disabled women - A Post Colonial Approach*. Unpublished CIHR Post-Doctoral Research Fellowship, Health Care Technology and Place Program, administered by the University of Toronto, undertaken at the University of Glasgow.
- Kerr, A., & Shakespeare, T. (2002). *Genetic politics: From Eugenics to Genome*. Cheltenham: New Clarion Press.
- Leach Sculley, J. (2002). Post modern disorder: Encounters with molecular models of disability. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity embodying Disability Theory* (pp. 48-61). London: Continuum.
- Lisi, D. (1993). Found voices: Women, disability and cultural transformation. In M. Willmuth & L. Holcomb (Eds.), *Women With disabilities: Found voices* (pp. 195-209). New York: Harrington Park Press.
- McDowell, L. (1999). *Gender, identity and place: Understanding Feminist Geographies*. Oxford: Polity Press.
- Michalko, R. (2002). Estranged familiarity. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity embodying Disability* (pp. 175-183). London: Continuum.
- Morris, J. (1991). Us and Them? Community care and disability. *Critical Social Policy*, 33, 22-39.
- Morris, J. (1997). Framed: A Feminist Perspective. In A. Pointon & D. Davis (Eds.), *Framed: Interrogating disability into the media* (pp. 21-30). London: BFI.
- Mostert, M. (2002). Useless eaters: Disability as genocidal marker in Nazi Germany. *The Journal of Special Education*, 36(3), p. 155-168.
- Nussbaum, M. (2006). *Frontiers of justice: Disability nationality and species membership*. Cambridge, MA: Belknap Press of Harvard University.
- Singer, P. (1994). *Rethinking life and death: The collapse of our traditional ethics*. New York: St. Martin's Griffin.

- Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Titchkosky, T. (2002). Cultural maps: Which way to disability? In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity embodying Disability Theory* (pp. 101-111). London: Continuum.
- Tremain, S. (2002). On the subject of impairment. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity embodying Disability Theory* (pp. 32-47). London: Continuum.
- Wolbring, G. (2002). *Rationale for the establishment of an International Center for Bioethics, Culture and Disability* (pp. 1-5). Internet [www.bioethicsanddisability.org](http://www.bioethicsanddisability.org) (9/11/2002).
- Young, I. (1997). The scaling of bodies and the politics of identity. In L. McDowell & J. Sharp (Eds.), *Space, gender and knowledge: Feminist readings* (pp. 218-231). London: Arnold.

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