

# Manipulating practices

A critical physiotherapy reader

---

Barbara E. Gibson, David A. Nicholls, Jenny Setchell  
and Karen Synne Groven (eds.)



## CHAPTER 1

# Post-critical physiotherapy ethics: A commitment to openness

Barbara E. Gibson | Department of Physical Therapy, University of Toronto / Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

### Abstract

This chapter sketches out the parameters for a (post-)critical physiotherapy ethics that reframes moral practice in terms of a commitment to openness. Dominant forms of contemporary bioethics tend to universalize the subject as a bearer of rights devoid of history, particularity, relationships, or social location. In the chapter, I build from critical and postmodern theories to examine ethical moments of radical openness towards disassembling habits of thought in physiotherapy. An open approach is not an ethics of adherence to universal rules or principles, but rather one that seeks to challenge ingrained norms, avoiding stasis and opening up new possibilities for practice by breaking down binary categories such as normal/abnormal, health/illness and self/other. My intent is not to provide a prescriptive set of rules for determining action, but to outline a method of analysis that can be

employed to understand the multiple effects of physiotherapy practices some of which are unintended, potentially harmful and largely obscured from view. The chapter includes a practice-based application to a case in children's rehabilitation.

## Introduction

Consistent with the aims of this book, my intent in this chapter is to outline a *critical* approach to physiotherapy ethics. However, it would perhaps be more accurate to state that my task is to explicate how any critical work is concerned with ethics. Physiotherapists, like most health professionals, are trained in a narrow version of bioethics that emphasizes juridical rules and top down application of principles. This training may obscure the link between criticality and ethics. Criticality is by its definition emancipatory, dedicated to surfacing “the development and continuation of inequalities in society, especially for those members of society with particular social characteristics, including socio-economic status, gender, sexual orientation, cultural background and disability” (Calhoun, 1995). Thus, doing critical work is also doing the work of ethics (or more precisely, normative ethics) in that it seeks to understand and redress systemic harms perpetrated in contemporary life. The ethics of openness I propose draws from postmodern strands of critical work (“post-critical”) to illuminate some of the most entrenched ideas in physiotherapy towards building moral practices.

Ethics is concerned with questions of how people ought to act. It is not limited to specific acts and defined moral codes, but encompasses all actions, practices, ideas, and systems that may be harmful or helpful in various ways. It asks questions like: How should people act? What do people think is right? How do we take moral knowledge and put it into practice? And what does “right” even

mean? (Mastin, 2008). Critical ethics focuses these questions in particular ways, asking:

- What do people take for granted as right or true?
- How did they come to think this way?
- What are the unintended or hidden effects of current dominant modes of thinking and acting?
- What alternatives are available and what are the possible effects of implementing these?

In what follows, I sketch out the parameters of a post-critical “ethics of openness” for physiotherapy. First, I briefly review the dominant approaches to bioethics and why these are increasingly inadequate for informing practice. I then review some key parameters of post-critical theory, incorporating an example from children’s rehabilitation, to outline the implications for an open approach to physiotherapy ethics.

## Mainstream bioethics

Mainstream bioethics<sup>1</sup> is grounded in dominant traditions of liberal humanism which emphasizes autonomy, independence and the rational application of abstract rules and principles. Consistent with this conceptual mooring is an emphasis on particular kinds of problems, many of which revolve around issues of choice and consent, access to treatment, fair processes and rational decision-making (Shildrick, 2005). Addressing ethical problems is achieved through rational deliberation of autonomous individuals who draw on principles or precedents to produce logical, objectively supportable actions (Murray & Holmes, 2009).

---

1 Bioethics is a sub-field of ethics oriented to the examination of ethical issues in health care, health science/research, and health policy

The most dominant ethical approaches used in healthcare training and practice rely on some version of consequentialism to putatively tabulate a balance sheet of “objective” risks and benefits to determine the best course of action. The weighing of options is guided by values and principles, most commonly the “Georgetown mantra” of Autonomy, Beneficence, Non-maleficence, and Justice (Beauchamp & Childress, 2013). The teaching and application of these frameworks usually takes the form of a review of facts, an assessment of how the principles apply, and deductive processes and debates directed at choosing what to do (see for example: Swisher, Arslanian & Davis, 2005; Enck, 2014; McDonald, Rodney & Starzomski, 2001). There is nothing inherently wrong with these frameworks that I have used in my own teaching to help students organize their thoughts and arguments. At a minimum, these approaches help to illuminate the ethical dimensions of an issue and mitigate over-reliance on regulation and law. Nevertheless, as I explore below, these approaches have limited utility in identifying and addressing the most deeply entrenched and pervasive social problems that are taken for granted as “just the way things are”.

Mainstream bioethics is not monolithic, however, and there are some alternatives to the rationalist project outlined above. Most notably, virtue ethics and its expression in narrative approaches to healthcare ethics are gaining some traction in professional education (Goodrich, Jean, Irvine & Boccher-Lattimore, 2005; Kinsella & Pitman, 2012). Virtue ethics as an approach has its basis in the virtuous traits that make up an individual’s character and is grounded in notions of practical wisdom or *phronesis* (Kinsella & Pitman, 2012). In healthcare, narrative approaches extend this tradition by drawing on patient stories to stimulate professional reflection and learning. They thus differ from more common approaches that assume a relatively context-free application of universally derived principles exercised by rational agents. Murray and Holmes (2009)

note, however, that virtue ethics is rarely taken seriously in clinical environments.

Rationalistic approaches to bioethics are consistent with contemporary liberal humanism that has its roots in 17th century enlightenment philosophy. Rene Descartes' now famous declaration "I think therefore I am" separated mind and body into two distinct substances, each with a different essential nature (Mehta 2011). The body was viewed as a physical material object, while the mind was positioned as the locus of knowledge. This separation of a thinking-mind from a sensate-body grounds the rational autonomous subject of modern medicine and bioethics.

Principlism provides the most compelling example of the dominance of Enlightenment reasoning in bioethics. Originally proposed by Beauchamp and Childress in 1985, and now the subject of seven editions of the *Principles of Biomedical Ethics* (Beauchamp & Childress, 2013), principlism espouses that all persons share a common morality that derives from certain transhistorical and transcultural principles that are putatively immanent across humankind. A stable, individuated, autonomous subject - disembodied and devoid of history, culture or context - is presumed to engage in logico-deductive processes in applying principles to produce ethical judgements. This tendency to universalize subjects both as moral agents and as objects of power has been criticized for reflecting neoliberal assumptions of individualism and future-oriented decision-making that are foreign to many cultures and groups (Kelly, 2003). Although there has been a shift to recognizing notions of "interdependence" in mainstream bioethics including principlism (Beauchamp & Childress, 2013), the valorisation of autonomy and individualism persists.

Mainstream bioethics has been the subject of criticism on several fronts from diverse disciplines. The most sustained and influential critique of these comes from feminist scholars who have long

noted bioethics' reluctance to engage with issues of power and privilege. Power-focused ethical work, they suggest, exposes actions and practices that perpetuate pervasive patterns of marginalization and oppression. Such an ethics views situated relations and hierarchies as integral to the understanding of any moral context, raising questions about the social basis for decisions at all levels (Sherwin, 1998; 2008). Critical strands of feminist ethics are concerned with how oppressive social arrangements become internalized by individuals or groups and misrecognized as "natural". Ethical deliberation is concerned with illuminating the forces of oppression that act on persons and by doing so contributing to social change. Sherwin (2008) uses the example of prenatal testing, suggesting that the traditional bioethical focus on consent (competence, disclosure, understanding, and voluntariness) is silent regarding the broader political question of why a woman may want to avoid the birth of a child with a disability. Such an expanded ethics would not only attend to the requirements of consent, but also consider, for example, the social assumptions regarding disability and quality of life that mediate how choices are constructed and weighed. Moreover, feminist and other forms of critical bioethics emphasize the political and historical situatedness of problems and people (Kelly, 2003). They acknowledge that the particulars of gender, race, and disability, for example, are not neutral in bioethical deliberation, but shape how problems are constructed and addressed, which problems receive attention and by whom (Kelly, 2003).

Emergent postmodern strands of critical bioethics extend power-focused feminist critiques by looking beyond the material organization of power hierarchies toward problematizing the epistemological assumptions that ground medicine and liberal humanism more broadly. Until relatively recently, most critical approaches to bioethics have adopted primarily historical-materialist views of power expressed in identity politics. As Shildrick (2005) notes,

this ethics of *distinction* persists in presupposing an independent subject as a bearer of individual (or group) rights. Rights are held by the body-contained-self protecting it from incursion from the outside, marking its independence from others and emphasizing its separation and distinct interests. The divisions of people by gender, race, disability and other identity categories reproduce this separation. Postmodernism challenges these divisions by positing irreducible differences and connections amongst all persons (Gibson, 2006; Price & Shildrick, 1998; Shildrick, 2000). A radical postmodern ethic thus reconfigures the relationship between self and other in terms of shared vulnerabilities, a becoming-with-others where categorizations and bodily boundaries are blurred. This blurring of subjectivities is a radical departure from liberal humanism and its conciliatory notions of “interdependence” that creates a space for different ways of understanding and approaching bioethical challenges and responsibilities.

It is here that I situate my discussion of a post-critical ethics of openness for physiotherapy. The ethical approach I sketch out in the remainder of this chapter is largely based on the work of Margrit Shildrick and her “post-conventional” critique of mainstream bioethics (Shildrick, 1997; 2005). I have written about this elsewhere, most notably in my book *Rehabilitation: a post-critical approach* (2016). In the remainder of this chapter, my goal is to explicitly apply these ideas to physiotherapy, towards disassembling habits of thought and providing a methodology for identifying the hidden, less obvious, sources of harm perpetrated in quotidian practices. In so doing, I re-examine the “good” that physiotherapy can offer.

## **An ethics of openness**

The ethics of openness I describe draws from both postmodern and critical theories and their shared critiques of the dominance of the

Enlightenment philosophy in contemporary life (Agger, 1991). The rational scientific project is deeply ingrained in the liberal humanism of western societies and finds expression in the health sciences, including physiotherapy, which have relegated other modes of understanding to the margins (Gibson, 2016b). Biomedical sciences assume a positivist epistemology (way of knowing), wherein a stable reality can be discovered through scientific observation and hypothetico-deductive reasoning. Said differently, phenomena such as health, disability, or quality of life are assumed to pre-exist their discovery and it is the task of science to reveal their objective properties (Mehta, 2011).

Post-critical approaches reject the notion of stable objective truths and instead assert that all knowledge is perspectival and relational. Simply put, knowledge is *produced by people* rather than existing “out there” waiting to be discovered. It is thus always subject to historical, cultural, political and other contextual contingencies that influence how the world is interpreted. “Disability”, for example, is one way of understanding and labelling particular kinds of observed human characteristics, but the kinds of differences that are made relevant, and the category itself, are historically produced human constructions that are always open to revision. Moreover, post-critical approaches are concerned with how power shapes knowledge, that is, what (and whose) interpretations persist and why. Power is not limited to an examination of the power one group exerts over another (as with power-focused feminist ethics), but includes the hidden, less obvious ways that the taken-for-granted goes unexamined and the ensuing consequences (Eakin, Robertson, Poland, Coburn, & Edwards, 1996).

So far, I have identified a number of post-critical ideas that have relevance for a reconsidered physiotherapy ethics: an examination of power in terms of the taken-for-granted, a critique of the separation of mind/body and other dualisms, and a relational

epistemology that acknowledges the constructed nature of knowledge. Collectively these ideas suggest that a post-critical bioethics is less concerned with adherence to universal rules or principles, but rather continually challenging ingrained norms and assumptions towards opening up new possibilities for practice (Shildrick, 1997). Such an approach can be mobilized to scrutinize unreflective assumptions that organize physiotherapy practices, not necessarily to discard them, but to appreciate more fully the range of their effects towards a deeper ethical engagement.

An ethics of openness is the normative expression of a post-critical epistemology, providing a methodology for identifying, analysing and addressing the ethical dimensions of physiotherapy practice. An open approach extends the range of “practice dilemmas” beyond individual patient-practitioner encounters to ask anew, What are we (physiotherapists) doing and why? In so doing, physiotherapists can develop an increased sensitivity to the multiple hidden effects of practice and their unintended harms. For example, all of the ways that health practitioners assess, label and treat bodily impairments contribute to sustaining ideas that disabled people’s bodies are problems that need to be fixed (Gibson, 2014; 2016a). While physiotherapy may be helpful in many ways that disabled people welcome, it also has this unintended effect that is rarely acknowledged. Physiotherapy ethics is traditionally more concerned with discussing risks and benefits of treatment, not with these broader harms that reflect and extend how disability and disabled people are viewed in society. A post-critical physiotherapy ethics thus aligns with postmodern approaches to disability studies in questioning how disability is understood and with what effects (Stiker, 1999; Shildrick, 2000; Goodley, Lawthorn & Runswick Cole, 2014; Gibson 2016c).

An ethics of openness is one of continually questioning the most every day, ingrained, accepted and “evidenced-based”

physiotherapy practices. Openness is about *doubt*, that is, doubting the unassailability of the accepted truths of physiotherapy and health care. Ingrained ideas, practices and principles are never settled but always open to revision. Moreover, it is perhaps those practices that appear devoid of ethical content that require the closest scrutiny. An ethics of openness, like all critical work, requires ongoing commitment to thinking against the grain.

## Quinn and the trampoline

An example helps to elucidate how an ethics of openness can be mobilized in physiotherapy practice. In a recent Canadian study in a children's rehabilitation hospital (Setchell, Abrams, Thille, Mistry & Gibson, 2017) we conducted observations of outpatient clinical encounters between health professionals, children with muscular dystrophy and their parents. In the following excerpt from the data, a physiotherapist (QuinnPT) and a parent (Mom) are discussing the family's recent purchase of a trampoline for their eight year-old son (Cameron):

*QuinnPT started with, "Okay, here's the thing," and Mom immediately made a face like she didn't want to hear anything bad about the trampoline. QuinnPT talked about how Cameron's ankles had rotated a bit. Mom jumped in and said that he wears his shoes, which provide support. QuinnPT said, "Not really support for his ankles." Mom said she did not want to deny him the trampoline because "he really loves it!" QuinnPT nodded, but then began to list some of the things she was concerned about such as the pressure on his ankles and compression fractures. She added that she appreciates that he liked it, but was very concerned about compression fractures. Mom looked a bit upset about this as she looked over at Cameron, who was playing with his book. QuinnPT then added with a sympathetic tone, "It's not an activity*

*I'd recommend, but it's up to you three (the family), and I appreciate where you're coming from." Mom nodded but she didn't look happy. QuinnPT then changed the subject...*

The ethics of this scenario may not be immediately apparent, and/ or the “right thing” for the physiotherapist to do may seem relatively straightforward (even if challenging to execute). From a traditional bioethics approach, we could check off all the elements of a “valid” approach to client/family-centred decision making:

- Capacity: The young child is viewed as incapable of independent decision making, thus Quinn engages the parent as the substitute decision maker who is charged with determining what actions are in his best interests.
- Disclosure and Understanding: Quinn has acknowledged Mom's position but takes steps to ensure she is aware of the risks. Quinn educates Mom to ensure that she appreciates the potential consequences.
- Voluntariness: Quinn has assured Mom that the final decision rests with the family. She does not insist that they give up the trampoline.

Within traditional bioethics, we could view this as an issue of balancing an avoidance of harms (non-maleficence) with respecting the autonomous choices of the family. There may still be issues to quibble with, however, even from a traditional bioethics standpoint. For example, a frequent debate surrounds questions of if and how to engage children towards supporting their “emerging autonomy”. Moreover, more is going on in the example than an arid application of principles and rules, as is evident in Quinn's tone of sympathy and her affirmation that she appreciates where the family is “coming from”. It is often challenging when practitioners disagree

with patients and feel the weight of responsibility when advice is not followed. Ethical deliberation is thus often focused on debating the appropriate degree of persuasion and avoidance of “paternalism”. Approaching the example post-critically, however, reveals a different set of ethical questions.

I said above that an ethics of openness is an ethics of doubt. We can apply this thinking in the case at hand to examine what is taken for granted by the physiotherapist in terms of what is best for Cameron, and her assumed responsibilities towards him and his family. The excerpt provides a striking example of competing professional and personal *logics* (Mol, 2008). The physiotherapist constructs the trampoline as an object of risk around which a decision must be made. She weighs the harms and benefits according to the logics embedded in her profession, which include her responsibility to minimize health and safety risks. The logics of physiotherapy invariably will see fun as secondary to maintaining ankle alignment and reducing fracture risks. However, Mom, and presumably Cameron, do not approach the trampoline according to these same logics. While they likely share some of Quinn’s concern for safety, for them the trampoline engenders pleasure, opening a space wherein Cameron *becomes* playing-child rather than diseased-child. To further delineate this distinction and what it means for a physiotherapy ethics of openness, I need to briefly sketch out the postmodern notion of *becoming*.

## Becoming

The critique of the separation of mind and body takes its most radical turn in the postmodern rejection of the individuation of subjects. Deleuze and Guattari (1983; 1987) re-imagine the subject as a continual “becoming” neither encased by skin and organs nor defined by static categories such as sick/well, disabled/able-bodied,

male/female, gay/straight or even person/thing (Massumi, 1992). Becoming is active. A temporarily produced subject is, in the next moment, broken down and reconfigured to become anew (Gibson, 2006). Deleuze and Guatarri reimagine the static individual of fixed identity in terms of *assemblages* that can be thought of as temporary collections of heterogeneous human and non-human elements that might include bodies, objects, ideas, animals, places etc. ad infinitum. Becoming-assemblages are never settled and thus defy categorization. Instead of a concern with what things “are” or are not there is an appreciation of movement, of a never settled “AND” that is “neither one thing nor the other, it is always between two things” (Deleuze, 1995). Becoming thus resists categorizations embedded in, for example, contemporary healthcare and physiotherapy, and asks us to consider how things might be otherwise.

Returning to the example, the notion of becoming can be mobilized to recognize and reconfigure the ethics of the encounter. “Cameron” is constructed in many ways according to different logics and commitments. None of these are more real or true than any others are, yet they incite very different actions. The Cameron of traditional bioethics is a rights-bearing individual with (emerging) autonomy. As a child (another identity category), he is deemed incapable of independent decision-making, thus an autonomous adult (Mom) is granted decisional authority. The child and adult are individuated – the adult of bioethics is *the* (singular) substitute decision maker. There is no collective assemblage here. Regardless of whom is consulted, some-*one* must decide. A *substitute* sovereign subject must be designated when the child-patient is incapable of independent, rational choice.

The Cameron of physiotherapy is a set of clinical symptoms, facts and problems to be addressed (muscular dystrophy-Cameron). As with traditional bioethics, he is not devoid of context or relationships; it is recognized that he is part of a family with unique circumstances

and preferences. Nevertheless, these are contingencies that inform decision making without altering the fundamental logics of clinical care. Physiotherapy constructs its object as one of (existing or potential) physical deficiencies addressed through adherence to a regime of specific actions (exercises, splints) and avoidances (trampoline). The imperatives of client and family-centred care guard against the imposition of professional power, but leave intact the individuated subject who is compelled to choose (Mol, 2008). Moreover, while in theory all choices of a capable decision maker are meant to be respected and upheld, in practice choices that do not conform to the logics of physiotherapy are heavily scrutinized. Mom's emphatic declaration that "he really loves it!" is an unacceptable rationale when the physiotherapist weighs it against the possible physical dangers presented. "Loving it" can never be a good enough reason within the algorithms of ethico-clinical decision-making. The response, deeply embedded in professional logics, is to assume the parent does not fully understand, that the thing to do is "educate" (convince/enlighten). The non-compliant parent produces a deep anxiety for the physiotherapist who is unable to persuade her do what is right. Quinn declares in frustration- "it's up to you" whilst making it clear that she disapproves. Mom is positioned as the "bad-parent" who is putting her child at risk.

Considered through a post-critical ethics of openness, becoming-*cameron* is a multiple, co-existing and ever-changing AND. I have switched to a lower case "c" in *cameron's* name to signal the fluidity of becoming. He is patient-with-muscular dystrophy but also a boy-jumping-gleefully, and many other becoming-*camerons*. The assembling of clinic-physiotherapist-mom-disease-risks produces one configuration that can be contrasted to the *cameron* of trampoline-home-family-body sensations-pleasure. "Cameron" is both and neither of these constructions, a singular multiplicity that is always in flux, defying categorizations of child, muscular dystrophy,

symptoms, function, prognosis, autonomous, incapable, vulnerable, sick, well, disabled, etc. And, of course, the same approach opens up how we understand “physiotherapist”, “mom”, and the open assemblages of other material and affective elements that come together to collectively “do physiotherapy”, “do family”, “do cameron”.

In the face of such porous and unstable relations, the question arises of how ethics is even possible. If all is open and shifting, where is the ethical responsibility? Shildrick (2005) suggests that the consequentialist calculus of traditional bioethics is “no more than an exercise in management” largely devoid of ethical content (p. 12). Rather the task of ethics, she asserts, is to think beyond the boundaries of the familiar. Doing ethics then is a critical exercise in questioning predetermined categories, principles and logics whether these are those of traditional bioethics or those of physiotherapy/healthcare. The ethical moment is the moment of doubt (*aporia*), where the old rules may no longer apply and different categories and ways of knowing emerge. Doubt does not preclude action. Shildrick (2005) draws on Derrida’s notion of the undecidable as signalling a responsive and responsible ethics:

*(Derrida’s) argument is that in the face of complex and incommensurable demands that suggest at best a multiplicity of competing ways forward, the imposition of one set of moral principles rather than another simply sidesteps the need for ethical decision. Rather than an effort to engage with the undecidable, the resort to preexisting rules or laws represents a retreat to the security of the known, not a real encounter with the ethical issues in hand. (p. 11)*

A “real encounter” is one where existing modes of thought are “made strange” - an act of thinking for oneself. This is more challenging than it might seem. Nevertheless, it is the essence of criticality: questioning deeply held assumptions, principles, tenets and truths that are seldom reflected upon but which govern daily action.

In the study, the clinical team and researchers discussed what had transpired in the Quinn encounter. The clinicians suggested that the prohibition against jumping was primarily related to the risk of muscle breakdown/myoglobinuria associated with Cameron's medication. They stated that because of these risks "there really is no choice". Here was the moment of certainty, of rote application of biomedical logics of risk/benefit without doubt or questioning. There was "no choice" and therefore no ethical conundrum. According to the biomedical logics of healthcare, these risks *automatically* overrode considerations of pleasure. "He just loves it!" is not a sufficient rationale. The team did not see an ethical responsibility to doubt or temper this certainty; instead, they were confronted with an uncomfortable duty to "educate" the family towards getting rid of the dangerous trampoline. Yet, once these modes of thinking were laid bare through our discussions, while the team may not have immediately changed their practices, they decided quite easily that there were other ways of seeing the situation, other possible cameron's to consider. This realization did not provide a prescription of what to do, but opened up the conversation to admit other constellations of cameron/family/muscular dystrophy/pleasure that may be enacted or blocked through clinical practices. Ways that extend beyond "It's not an activity I'd recommend, but it's up to you".

## Conclusion as opening

A commitment to openness in physiotherapy requires a radical shift in habits of thought. Appreciating that most everyday practices of assessment, treatment, and education are imbued with ethical import requires physiotherapists to adopt a position of continual doubt. Setting aside the certainty of what patients need is aided by reconsidering "patients" in terms of multiple becomings (Setchell, Nicholls & Gibson, 2017). Instead of reasoning through

a set of objective problems, risks, and “contextual factors”, an open approach expands the moral imagination to consider irreducible and shifting connections and possibilities. Pleasure and risk, for example, are considered alongside each other, not in order to choose but to enable: to free up new creative possibilities that might not have been previously imagined. What could physiotherapy achieve in considering the becoming patient, in questioning how practices (re)produce the body-at-risk to the exclusion of other modes of doing and being? What compromises or affective appreciations might emerge? Such an ethics shifts and expands the logics of practices to embrace undecidability and thinking for oneself.

While an ethics of openness does not provide a framework for approaching ethical practice, it does provide a guiding question: *What are you doing when you are doing what you are doing?* (Gibson, 2016a). In other words, what are the effects of what you are doing - considered in the broadest possible terms? What are considered good outcomes and why? In pursuing preferred outcomes, what other effects are produced and what other possibilities are rendered impossible, for this patient and others? Here is the essence of criticality that I opened with at the beginning of the chapter. Providing ethical physiotherapy *care*, in the many senses of the term, is a tremendous task characterized by constant twists, turns, problems, frictions and complications that are never settled or straightforward. Doubt is difficult for professionals who are trained to be experts, whose job it is to know things, to have answers, to educate patients (Gibson, 2016a). Asking, “what are we doing”, however, is essential in avoiding complacency in our collective commitments to provide ethical care.

## Acknowledgements

Data presented in this chapter was drawn from a research study funded by the AMS Phoenix Program. Thanks to the study

participants who gave so generously of their time and insights. Thanks also to the study research team: Laura McAdam, Jenny Setchell, Thomas Abrams, Patty Thille, and Bhavnita Mistry. Barbara Gibson is supported by the Bloorview Children's Hospital Foundation Chair in Childhood Disability Studies.

## References

- Agger, B. (1991). Critical theory, poststructuralism, postmodernism: their sociological relevance. *Annual Review of Sociology*, 17, 105–31.
- Beauchamp, T.L. & Childress, J.F. (2013). *Principles of Biomedical Ethics*, (7<sup>th</sup> ed.). New York, NY: Oxford University Press.
- Calhoun, C. (1995). *Critical social theory: culture, history, and the challenge of difference*. Chichester: Wiley-Blackwell.
- Deleuze, G. (1995). *Negotiations: 1972–1990*. New York, NY: Columbia University Press.
- Deleuze, G. & Guattari, F. (1987) *A thousand plateaus: Capitalism and schizophrenia*. Minneapolis: University of Minnesota Press.
- Deleuze, G. & Guattari, F. (1983) *Anti-oedipus: Capitalism and schizophrenia*. Minneapolis: University of Minnesota Press.
- Eakin, J., Robertson, A., Poland, B., Coburn, D. & Edwards, R. (1996). Towards a critical social science perspective on health promotion research. *Health promotion international*, 11(2), 157–165.
- Enck, G. (2014) Six-step framework for ethical decision making. *Journal of health services research & policy*, 19(1), 62–64.
- Gibson, B.E. (2016a). *Rehabilitation: A post-critical approach*. Boca Raton, FL: CRC Press.
- Gibson, B.E. (2016b). Moving rehabilitation. In *Rehabilitation: A post-critical approach* (1–26). Boca Raton, FL: CRC Press.
- Gibson, B.E. (2016c). Disability/Normality (Ch 2). In *Rehabilitation: A post-critical approach* (27–50). Boca Raton, FL: CRC Press.
- Gibson, B. E. (2014). Parallels and problems of normalization in rehabilitation and universal design: enabling connectivities. *Disability and rehabilitation*, 36(16), 1328–1333.
- Gibson, B. E. (2006). Disability, connectivity and transgressing the autonomous body. *Journal of Medical Humanities*, 27(3), 187–196.

- Goodley, D., Lawthom, R. & Cole, K. R. (2014). Posthuman disability studies. *Subjectivity*, 7(4), 342–361.
- Goodrich, T. J., Irvine, C. A. & Boccher-Lattimore, D. (2005). Narrative ethics as collaboration: a four-session curriculum. *Families, Systems & Health*, 23(3), 348–357.
- Kelly, S. E. (2003). Bioethics and rural health: theorizing place, space, and subjects. *Social Science & Medicine*, 56(11), 2277–2288.
- Kinsella, E. A. & Pitman, A. (2012). Engaging phronesis in professional practice and education. In *Phronesis as professional knowledge* (1–11). Rotterdam: SensePublishers.
- Massumi, B. (1992). *A user's guide to capitalism and schizophrenia: Deviations from Deleuze and Guattari*. Cambridge, Massachusetts: MIT Press.
- Mastin, L. (2008) *The basics of philosophy*. Retrieved from: [http://www.philosophybasics.com/branch\\_ethics.html](http://www.philosophybasics.com/branch_ethics.html).
- McDonald, M., Rodney, P. & Starzomski, R. (2001). *A framework for ethical decision-making*. Retrieved from: <http://ethics.ubc.ca/upload/a%20framework%20for%20ethical%20decision-making.pdf/>.
- Mehta, N. (2011). Mind-body dualism: A critique from a health perspective. *Mens Sana Monographs*, 9(1), 202–209.
- Mol, A. (2008) *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge.
- Murray, S.J. & Holmes, D. (2009). Introduction: Towards a Critical Bioethics. In S.J. Murray & D. Holmes (eds.), *Critical interventions in the ethics of healthcare: Challenging the principle of autonomy in bioethics* (1–11). New York: Routledge.
- Price, J. & Shildrick, M. (1998). Uncertain thoughts on the disabled body. In M. Shildrick & J. Price (eds.), *Vital signs: feminist reconfigurations of the bio/logical body* (224–249). Edinburgh: Edinburgh University Press.
- Setchell, J., Abrams, T., Thille, P., Mistry, B. & Gibson, B.E. (2017). Enhancing human aspects of care with young people with Muscular Dystrophy: Results from a participatory qualitative study involving clinicians. *Child: Care, Health & Development*. E-print, DOI: <https://doi.org/10.1111/cch.12526>.
- Setchell, J., Nicholls, D. A. & Gibson, B. E. (2017). Objecting: Multiplicity and the practice of physiotherapy. *Health*. E-print, DOI: 1363459316688519.

- Sherwin, S. (2008). Whither bioethics? How feminism can help reorient bioethics. *IJFAB: International Journal of Feminist Approaches to Bioethics*, 1(1), 7–27.
- Sherwin, S. (1998). A relational approach to autonomy in healthcare. In S. Sherwin (Ed.), *The politics of women's health: Exploring agency and autonomy*. (19 – 47). Philadelphia, PA: Temple University Press.
- Shildrick, M. (2005). Beyond the body of bioethics: Challenging the conventions. In M. Shildrick & R. Mykitiuk (eds.), *Ethics of the body; Postconventional Challenges* (1–28). Cambridge, MA: MIT Press.
- Shildrick, M. (2000). Becoming vulnerable: Contagious encounters and the ethics of risk. *Journal of Medical Humanities*, 21(4), 215–227.
- Shildrick, M. (1997) *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)ethics*. Taylor and Francis. Kindle Edition.
- Stiker, H.J. (1999). The birth of rehabilitation. In *A history of disability*. (121–89). Ann Arbor: University of Michigan Press
- Swisher, L. L. D., Arslanian, L. E. & Davis, C. M. (2005). The realm-individual process-situation (RIPS) model of ethical decision-making. *HPA Resource*, 5(3), 1–7.