Values and Principles of Teaching Critical Disability Studies in a Physical Therapy Curriculum: Reflections from a 25-Year Journey – Part 1: Critical Disability Studies Value Framework

Karen K. Yoshida, PhD; Hazel Self; Heather Willis, BA

The field of disability studies (DS) has grown rapidly in North America and around the world over the past 20 years.1–3 Canada has seven designated DS programmes across the country and DS courses in other areas of concentration in a variety of disciplines, such as the humanities.4 DS is now also being taught in non-DS health professional academic programmes—including physical and occupational therapy and rehabilitation courses in the United States.5 Consistent with these initiatives, Judith Heussman’s keynote address at the 2007 World Congress of Physical Therapy6 emphasized the importance of physical therapists working with the community with disabilities.

These developments guide the perspectives described in this editorial. In Canada, DS has not secured a substantial foothold, in general, in the allied health professional programmes—physical therapy (PT), occupational therapy, speech language pathology, and social work. However, in the Department of Physical Therapy at the University of Toronto, we have been developing content for, and teaching, critical disability studies (CDS) since the 1990s—more than 25 years. We began teaching DS at a time when no other PT programme in Canada offered this content and critical perspective to their students.

WHAT IS MEANT BY CRITICAL DISABILITY STUDIES?

CDS is an academic–activist scholarship that examines how bodily differences are constructed, represented, and produced as “disability” and sustained through dominant normative values, practices, and policies in industrial Western societies. We make a clear distinction between CDS and disability, understood as a medical condition. CDS scholarship values difference as part of the human experience,7 and this difference is exemplified in the growing cultural landscape by the emergence of disability arts, culture, and history. As a result, CDS is an alternative and transformative scholarship.

We share the common goal of imparting this important critical and alternative view of disability to PT students. We believe that CDS content and experiential learning will assist physical therapists to become agents of social change—to address social inequities in health care with their clients and the broader communities they serve, including the disability community. We use the terms disabled person and disabled people to politicize the experience of difference and to situate disability within social, cultural, economic, and political forces that push marginalized communities to the periphery of society.

In the following comments, we draw on bell hooks’s8 concepts of centring and being on the margins to frame the development and teaching of CDS scholarship in the Department of Physical Therapy at the University of Toronto. bell hooks8 spoke to her own and collective experiences with others in that she and they see the world as living on the edge and “seeing from both the outside in and the inside out.”8(p.xvi) CDS can be seen as scholarship that is on the edge, working toward locating itself more centrally within academia but not forgetting that being on the margins provides a valuable perspective. We view centring first as spatial, as positioning within a curriculum; in other words, where CDS sits within a program is important. We suggest that centring also refers to a focus on alternative knowledge—different ways of knowing and being. Essential to this is partnering with disabled people from diverse communities and foregrounding their lived experiences and embodied knowledge to develop a CDS curriculum.

Our remarks are organized as follows: First, Karen Yoshida briefly describes how she came to develop and teach a CDS curriculum in PT. She describes how her practical experience as a physical therapist and interactions in the Toronto disability community led her to
adopt a critical perspective on disability. These early experiences formed her values and principles of CDS pedagogy in general and specifically as the basis for incorporating CDS into PT education at the University of Toronto. Hazel Self and Heather Willis voice their own perspectives on the value of teaching CDS in PT.

We then discuss the four values or principles that we believe are important to guide the teaching of CDS in PT curricula. One value is developing and maintaining equitable partnerships in teaching, exemplified by the slogan “Nothing about us, without us.” As an example of meaningful partnerships, we have collaborated on this editorial as three colleagues who have worked together to develop this teaching content over the years and who have close ties to the disability community. We believe that PT academics and clinicians should

1. Embrace and work from a CDS standpoint.
2. State their relationship to disability.
3. Value the lived experience or embodied knowledge of disabled people.
4. Learn from, and work in regular partnership with, disability rights communities and disability consumer-led organizations.

JOURNEY TO CRITICAL DISABILITY STUDIES: CRITICAL ENCOUNTERS AND PERSONAL REFLECTIONS OF A PHYSICAL THERAPIST (KY)

During the early 1980s, when I was training as a physical therapist, several critical events occurred that made me reflect on and question my role as a physical therapist. One such event occurred during a clinical internship. My supervisor asked me to teach a client, Brian (a pseudonym), who lived with quadriplegia, how to transfer from chair to toilet. I studied how to teach this transfer and took my manual and a transfer board to meet Brian in the washroom the next day. Once we entered the stall, I realized immediately that neither what I had read in my textbook nor the transfer board was going to be useful in teaching Brian how to transfer to the toilet. I asked him what he needed, and he calmly answered, “Probably a Hoyer lift.”

This event was critical because it taught me that what I read in books might be of little help to clients and that their input was crucial during the rehabilitation process. I spoke to Brian and another client, Gail (another pseudonym), many times about the role of PT, and they became my first mentors. I completed my program in 1982 and worked for a year in an acute care hospital. During that time, I kept thinking back to that and other events, and I decided to do graduate work in the sociology of health and illness and the social inequalities in health.

My PhD dissertation, completed in 1991, was a sociological study of the lived experiences of people who had sustained a traumatic spinal cord injury and how they had reconstructed their identity and lives after their injury. This research furthered my understanding of the importance of incorporating the embodied experiences of disabled people into PT.

During this time, I also sought out other ways to learn from disabled people. I contacted Vic Willi, the executive director of the Centre for Independent Living in Toronto (CILT)—a non-profit organization run by disabled people for disabled people related to self-advocacy, peer support, and resources—and told him that I wanted to learn from the larger disabled community about their concerns about the rehabilitation process, community issues, and disability rights in Canada. Vic invited me to attend a community meeting of attendant service users who were lobbying the government for better services in this area. Self-directed attendant services refers to someone coming into the home of a disabled person and providing assistance with various activities of daily living, all under the disabled person’s direction. The idea that attendant services could help disabled people get on with their lives—work, school, leisure, and family—was a powerful one, and it seemed to be a contradiction of the physical self-sufficiency view that the rehabilitation process promoted for those living with long-term conditions. This meeting was important because it taught me the power of community and collective action.

At this point, I decided to immerse myself in the community. I served on the CILT board for 7 years (1982–1989), and this was a significant opportunity to become familiar with the issues, resources, and leadership in the disability rights community in Toronto. As I met people at board meetings and community events, I asked them how PT and rehabilitation could better serve their needs. I met with key leaders (including Hazel and Heather) to discuss the shortcomings of rehabilitation practice. Much of what they said aligned with my own experiences working in the field at the time: Disabled people lacked input into their own rehabilitation process and were inadequately prepared to re-enter society after rehabilitation; for their part, professionals assumed they knew what was best, they lacked knowledge of the disability experience, and they assumed that disability was a tragedy and a wholly negative existence.

I first met Karen at the meeting at CILT in 1986. I had a spinal cord injury (quadriplegia), was discharged from rehab in 1980, and was busy advocating for improved attendant services. I was also doing a lot of travelling and painting. I often thought about the huge disconnect between my rehab experience and the life I was now living in the community. I realized that none of my rehab team had any practical knowledge about the way my disability-related needs were being met in a non-medical environment—for example, living in a subsidized, accessible apartment; directing and training attendants; using accessible transportation; obtaining equipment to enhance independence—nor did they know that I was accomplishing activities such as flying, horseback riding, painting, and kayaking.
When Karen spoke about wanting to incorporate DS into the PT curriculum, I immediately welcomed the opportunity to influence the next generation of physical therapists. I wanted them to know what it takes for people living with lifelong conditions to rebuild their lives and take part in community life. I wanted to see rehabilitation become more relevant and practical, thereby giving hope. This was an opportunity to bridge the gap between the rehab environment and the lived experience in the community and to see that reality guiding the rehab process of the future. (HS)

From these discussions, it was clear that physical therapists required knowledge about disability that was not based on a medical model of deficits and deviations from arbitrary concepts of normal. Rather, the PT curriculum required a different view of disability, one that acknowledged it as a socially constructed phenomenon, and an understanding of how dominant, normative representations of disability have a negative impact on disabled people’s everyday lives. At the same time, it needed to promote an understanding of the embodied, lived knowledge of people who live differently. This paradigm shift in thinking about disability would represent a significant departure for physical therapists and PT.

**INTRODUCING CRITICAL DISABILITY STUDIES INTO A PHYSICAL THERAPY CURRICULUM: CREATING AND CAPITALIZING ON OPPORTUNITIES**

During the late 1980s, the PT program at the University of Toronto was changing its curriculum, creating opportunities to introduce new content and ideas into the program. The time was ripe for the development of a CDS course. In 1987, I suggested a CDS “selective” Disability in the Community course. This 6-week course was offered to 4th-year students and focused on the importance of a disabled person’s perspective and the community resources needed to get on with life. This selective was taught for 2 years and was well received by the students.

We were then able to get a full half-course included in the PT program. This was important because it meant that there would be a core course on CDS in the curriculum for the first time. It was also important to offer this course at the beginning of the program so that students could learn about an alternative view of disability alongside the biomedical view. This course, called Disability Perspectives and Physical Therapy, was a 12-week course offered in the fall of the 1st-year intake, beginning in September 1993. With input from my community colleagues, the course was grounded in four values and principles.

1. **Physical therapy academics and clinicians embrace and work from a critical disabilities studies standpoint**

   Clearly, working from a CDS standpoint requires learning and reading about these issues. The scholarship is quite extensive because the CDS literature has exploded over the past 20 years. What is most important is that instructors take a critical approach to disability. First, disability is not a universal, inherent deficit within people but is produced through particular practices, policies, and systems of oppression and discrimination that treat disabled people as marginalized others in various societies. It is beyond the scope of our comments here to provide a comprehensive list of references, but CDS is an interdisciplinary scholarship drawing from a variety of CDS and other critical social science perspectives.

2. **Physical therapy academics and clinicians state their relationship to disability**

   Stating one’s relationship to disability is an important critical act that has its roots in other activist disciplines, such as critical race or queer studies. The question “What is your relationship to disability?” is important for those who teach, speak, write, or do research related to disability. Its phrasing moves away from the limiting and binary structure of “Are you disabled or non-disabled?” and opens up opportunities for people to state their relationships, if any, to disability.

   My relationships to disability are multiple: I am a CDS scholar, ally, and advocate. I have family members who live with disabilities. I have worked with disabled colleagues and other disability-positive allies in research and teaching since 1987. My stated relationships with disability let others know where I am situated within the disability community.

   All experiences are important to the collective understanding of disability. This disclosure of one’s relationship to disability is important because it signifies one’s experiences with disability and ableism (oppression experienced by disabled people). Naming and discussing ableism and privilege is important because discussions on disability are often silent on these issues.

3. **Physical therapy academics and clinicians value the embodied knowledge of disabled people**

   Disabled people’s lived experience is a critical and essential element of CDS scholarship, one that PT educators must incorporate into teaching CDS. What we mean by *lived experience* is not just people’s perspectives of their own particular lives but also a perspective that acknowledges one’s life experiences embedded in the social circumstances (e.g., class, race, age) that influence one’s experiences. This lived experience also means acknowledging that there are shared or collective experiences among disabled people. This embodied knowledge of disability or difference needs to be at the forefront of teaching CDS.

   It wasn’t until I was exposed to the disability rights and independent living movements, and eventually the Social Model of Disability, that I began to realize the profound complexity of the relationships we have with those on whose expertise about our bodies we rely. Furthermore, the systems and structures within which this expertise is
produced create an unequal power dynamic between health professional and patient. It is not enough to simply understand the biomedical facts of our bodies; it is equally important to understand our lived experience and how it relates to and is affected by practice.

Karen Yoshida’s groundbreaking work of embedding a critical disability lens in the practice of PT has brought an important focus to this endeavour. Her approach acknowledges our embodied expertise as disabled people, and it positions us as partners in the education of the medical community with whom we interact to maintain our well-being and independence, thus fostering a reciprocal relationship of respect and knowledge sharing. (HW)

4. Physical therapy academics and clinicians learn from, and work in regular partnership with, disability rights communities and disability consumer–led organizations

In addition to this academic foundation, we strongly recommend that PT instructors in CDS gain community-based disability knowledge and experience. This knowledge and experience should focus on the current and enduring rights issues important in various disability communities. This grounding in daily and community issues is important for several reasons. CDS is not only an academic discipline but also an activist scholarship because it has deep roots in the disability rights community in the United States and Canada. Besides the knowledge and experience physical therapists gain by being involved in the disability community, their involvement signals an ongoing commitment. This sustained relationship and partnership is important for any work in which a physical therapist will engage.

CONCLUSION

These four broad values are essential for PT educators to teach CDS scholarship within a PT curriculum. They provide a pedagogical framework based on more than 25 years of collaborative teaching of CDS in the Department of Physical Therapy at the University of Toronto, and they are important topics that require additional discussion and debate. We continue to learn how to put these values into practice in ways that reinforce the shared perspective of, respect for, and commitment to CDS scholarship and activism in the academy and the disability community.

Part 2 of this editorial will focus on the CDS pedagogical framework and some essential teaching activities that we have developed in the Department of Physical Therapy.

REFERENCES

1. Pfeiffer D, Yoshida KK. Teaching disability studies in Canada and the United States. Disabil Stud Q. 1995;10(4):475–500. http://dx.doi.org/10.18061/dsq.v10i4.50592582.
2. Panitch M. Commentary 1 on “A multinational review of English language disability studies degrees and courses.” Disabil Stud Q [serial on the Internet]. 2009 [cited 2016 Jun 1];29(3). Available from: http://dsq-sds.org/article/view/953/1127.
3. Cushing P, Smith T. A multinational review of English language disability studies degrees and courses. Disabil Stud Q [serial on the Internet]. 2009 [cited 2016 Jun 1];29(3). Available from: http://dsq-sds.org/article/view/940/1121. http://dx.doi.org/10.18061/dsq.v29i3.940.
4. Snyder SL, Brueggeman B, Garland-Thomson R, editors. Disability studies: enabling the humanities. New York: MLA; 2002.
5. Block P. Disability studies in the belly of the beast. Disabil Stud Q [serial on the Internet]. 2004 [cited 2016 Jun 1];24(4). Available from: http://dsq-sds.org/article/view/884/1059. http://dx.doi.org/10.18061/dsq.v24i4.884.
6. Heussman J. Keynote address. World Congress of Physical Therapy; 2007 Jun 2–6; Vancouver, BC.
7. Society for Disability Studies. Definition of disability [Internet]. Buffalo (NY): The Society; 2016 [cited 2016 April 13]. Available from: http://www.dsdisstudies.org.
8. hooks b. Feminist theory: from the margins to the center. 2nd ed. London: Pluto Press; 2000.
9. Charlton JI. Nothing about us, without us: disability oppression and empowerment. Berkeley: University of California Press; 2000.
10. Davis L. The end of normal: identity in a biocultural era. Ann Arbor: University of Michigan Press; 2013.
11. Wendall S. The rejected body: feminist philosophical reflections on disability. New York: Routledge; 1996.
12. Siebers T. Disability theory. Corporealities: discourses of disability. Ann Arbor: University of Michigan Press; 2008. http://dx.doi.org/10.3998/mpub.309723.
13. Titchkosky T, Michalko R, editors. Rethinking normalcy: a disability studies reader. Toronto: Canadian Scholar’s Press; 2009.
14. Williams SJ, Bendelow G. The lived body: sociological themes, embodied issues. London, UK: Routledge; 1998. http://dx.doi.org/10.4324/9780203260241.
15. Corker M, Shakespeare T, editors. Disability/postmodernity: embodying disability theory. London: Continuum; 2002.
16. LeFrancois BL, Menzies R, Reaume G. Mad matters: a critical reader in Canadian mad studies. Toronto: Canadian Scholars Press; 2013.
17. O’Toole C. Disclosing our relationships to disabilities: an invitation for disability studies scholars. Disabil Stud Q [serial on the Internet]. 2013 [cited 2016 Jun 1];33(2). Available from: http://dsq-sds.org/article/view/3708/3226.

DOI:10.3138/ptc.68.4.GEE2