

Manipulating practices

A critical physiotherapy reader

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CHAPTER 9

Unbinding physiotherapy knowledge. Critical disability studies' epistemology: moving towards a socially-just physiotherapy profession

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Abstract

In this chapter, I describe a critical alternative epistemology for Critical Disability Studies. Epistemology is the study of what is knowledge and truth. An epistemology delineates what is knowledge, who can claim knowledge and how it is assessed through a particular worldview. I base my critical disability studies epistemology (CDSE) on Afro-centric feminist epistemology as articulated by Collins and augmented by bell hooks. This Afro-centric feminist epistemology, in opposition to a euro-centric masculinist epistemology, embraces the concept of interlocking, diverse forms of oppression and promotes resistance. A CDSE centers on the generation and validation of knowledge through critical

reflection of embodied experiences, active dialogue emphasizing connectedness to others and community, and the ethics of care - emotionality and empathy as investment and accountability related to one's relationship(s) to disability. Incorporating a CDSE will support the further development of critically reflexive and analytical physiotherapy students, clinicians, teachers, researchers and policy makers to promote more socially just PT practices.

Introduction

Physiotherapy knowledge has moved from being a “craft” occupation (Miles-Tapping, 1989), to a clinical science-based knowledge dominated by evidence-based and health science discourses (Jette et al., 2003). One important health science approach that has influenced health professions in Canada and elsewhere is the Social Determinants of Health (SDH) approach (Public Health Agency of Canada, 2011). The SDH approach takes as its focus that health is based on many influences of which health services is only one component. An SDM approach examines the context of disease and ill health and promotes the idea that while individual behaviour towards health is important, this behaviour is conditioned and influenced by the social circumstances and social locations of individuals, communities and populations. Proponents of the SDH approach indicate that people's socio-economic status, occupation, and social networks are the most important influences on health (Public Health Agency of Canada, 2011). The importance of the SDH approach is that it has encouraged health professions in Canada to look explicitly and intentionally at the “social” aspects and to incorporate this approach within the content and practice of their professional activities.

This turn towards the social is evident within physiotherapy. Proponents of the national and international PT professional

community have moved to articulate and conceptualize PT as a socially-informed and socially-producing knowledge base (see Critical Physiotherapy Network Website). This includes explicating, interrogating and disrupting the “physicality” of physical therapy. Over the years, work within the profession has taken a more “social” approach to problematizing and re-conceptualizing key concepts and issues within physiotherapy (Cott, Finch, Gasner, Yoshida, Thomas, & Verrier, 1995; Gibson & Teachman, 2012; Nicholls, Gibson & Fadyl, 2015; Yoshida, 1993; Yoshida, 1994) such as the concepts of movement, self-conceptions, and disability. Historically and currently, the concept of disability has been predominantly defined in individual/medical and physical terms as a deficit, defect or lack within the body that requires some intervention to ameliorate or reduce the disability. Given this view, those living with disability were/are seen as unable to engage in everyday aspects of life – living in the community, school, work, relationships, travel, having intimate relationships, and raising children. Disability advocates/activists as early as the 1960s and 1970s in the United States, Canada and United Kingdom challenged the individual/medical view of disability and put forth a social model view of disability (Dejong, 1979; Oliver, 1990; Union of the Physically Impaired Against Segregation [UPIAS], 1975). In this framework, notions of disability are considered to be created by the inaccessible physical environments, policies and practices of an abelist or able-bodied majority society (UPIAS, 1975; Oliver, 1990). These grass roots organizations called for equal rights for disabled people and seeded the development of academic scholarships in Disability Studies in the United States, Canada and United Kingdom (Dejong, 1979; Shakespeare, 2010; Driedger, 1989) and globally with the United Nations’ Convention for the rights of People with Disabilities (United Nations, 2006). In the United States

and Canada, Disability Studies as a discipline has distanced itself from deficit models of disability commonly used in medicine, rehabilitation and special education (Linton, 1998). However, if traditional professional views of disability and practices are to change, there is a need for direct engagement of Disability Studies scholarship in these disciplines (Chen, Kirchner & Kudlick, 2004; Block, 2004; Yoshida, Self, & Willis, 2016). There is scepticism, however, among Disability Studies scholars toward this excursion into non-Disability Studies academic programs. In addition, while there are a few healthcare professional programs that have CDS content/programs, there is still a lack of acceptance and acknowledgement that CDS is relevant or legitimate knowledge. This tension provides the context for this chapter.

As both a DS scholar and physiotherapist, I began teaching Critical Disability Studies (CDS) in the Department of Physical Therapy at the University of Toronto, Canada, more than 20 years ago. I have detailed key principles and values needed to teach CDS (Yoshida et al., 2016), critical pedagogical imperatives, and some of the major teaching content as well (Yoshida, Self, Willis & Rose, 2017). I argue here that it is important to incorporate CDS into current physiotherapy (PT) knowledge, as it provides a critical alternative epistemology (CDSE). Epistemology is the study of what is knowledge and truth. An epistemology delineates what is knowledge, who can claim knowledge and how it is assessed through a particular worldview.

I suggest that a CDSE unbinds or opens up PT knowledge to relevant, alternative knowledge claims and critical analyses and therefore would lead to more socially just PT pedagogies and practices. CDSE coupled with social justice pedagogies and practices within PT can support the further development of critically reflexive and analytical students, clinicians, researchers and policy makers within PT and rehabilitation.

In this chapter, I offer a CDSE – what it consists of, and its merits for PT education and the profession as a whole. Theoretically, I bring together Afro-centric Feminism epistemology (Collins, 1991), feminism and praxis (hooks, 2000), and disability and social justice (Berne, 2015; Mingus, 2011) to underpin the CDSE that I use in PT education at the University of Toronto. The writings of Collins and hooks have been important touchpoints for my teaching and research over the past ten years. In what follows I : 1) state my positionality (social locations); 2) discuss the four basic tenets of Afro-centric Feminist epistemology (Collins 1991) – concrete experience, use of dialogue, talking from the heart (expression, emotions and empathy) and ethics of personal accountability, and show how this standpoint differs from euro-centric masculinist epistemology; 3) describe how I have shaped a CDSE using Collins and bell hooks¹ works as a foundation. In doing this, I do not conflate disability, gender and race, but seek to illustrate their similarities and acknowledge their important differences; and 4) discuss the importance of physiotherapy taking up this alternative epistemology of disability to support socially just PT pedagogies and practices. I also will envision a future PT profession that incorporates CDS epistemology in terms of its key features.

I: Positionality and background to this chapter

Stating one's positionality (i.e. one's social locations and relationships to disability) provides the reader with information to understand how experiences shape the focus and analysis of one's work and in this case, this chapter. It is also an important element of a CDSE that I describe later. I am a non-disabled, cis-gendered, Canadian

¹ bell hooks does not capitalize her first and last name

woman of third generation Japanese ancestry, raised in a working class home. I am privileged as a tenured professor, located in an academic department of physical therapy, positioned within a Rehabilitation Science Institute and embedded within a Faculty of Medicine. I work in a public, research intensive university in Canada. My graduate training was in the sociology of health and illness and the sociology of disability in a graduate program that emphasized the examination of the social inequities of health.

My relationships to disability (O’Toole, 2013) are multiple. I am a Critical Disability Studies scholar and ally. I have disabled family members. I have worked with disabled colleagues and other disability-positive allies in research and teaching since 1987. In my work, I place the word “critical” in front of Disability Studies to distinguish it clearly from disability as a medical/clinical issue, given the context in which I work. In this paper, I use “disabled person or people” as a politicized term to signify that disability is a positive identity for many people and that disability is a social product(s) of diverse and multiple social relations within a western capitalist society.

II: Afro-centric feminist epistemology (Collins)

Patricia Hill Collins’ articulation of Afro-centric Feminist epistemology (AFE) (Collins, 1991) and bell hooks’ feminist theory (2000) provide the foundation for this chapter. These two seminal feminist pieces center issues of domination, multiple oppressions, and resistance. They provide a strong foundation for my articulation of Critical Disability Studies epistemology. In this chapter, I summarize the key points of Collins’ AFE that I believe are important to a CDSE. In writing this summary, I remain respectful of and use her specific wording of identifications throughout my paper.

According to Collins (1991), the AFE epistemological standpoint is oppositional to the euro-centric, masculinist knowledge validation process that dominates academic discourse. Black women have to struggle against white males' interpretations of the world to articulate a self-defined (black woman's) viewpoint, which can be seen as subjugated knowledge (Collins, 1991). Within this web of domination, both Collins (1991) and hooks (2000) reject the notion of separate oppressions (i.e. gender, race and class), and the adding on of other oppressions (additive model of oppression) in viewing domination. They propose reconceptualizing relations of domination for Black women as a system of *interlocking* oppressions of race, class, and gender because these oppressions arise from an encompassing, historical system of dominance. For Black women, race, class and gender are most important. This interlocking approach promotes thinking explicitly about these oppressions and other forms of oppression, such as religion, age, ability/disability and sexual orientation, the interplay between them and how they may work to dominate others.

In placing African-American women and other marginalized groups in the center of analysis, one can see how groups have various amounts of privilege and penalty (oppression) in a historically created system (Collins, 1991). For example, white women can be penalized by their gender, but privileged by ability. A white disabled person may have privilege in some setting and a racialized disabled person may not. Within a system of interlocking oppressions and, depending on their social circumstances, a person may be a member of an oppressed group (disabled), may be an oppressor (male) and thus simultaneously oppressor and oppressed (Collins, 1991). For example, domination related to race and gender produces racism and sexism (hooks, 2000). These oppressions exclude people from having choice and opportunities and most importantly, socializes the oppressed to believe that their oppression is natural.

hooks (2000) describes sexism as the process whereby individuals are socialized or taught/learn to behave in particular ways that make them act in compliance with oppressive dominant social structures and institutions. For example, Black women are taught that relationships with other Black women will not enrich their lives and are taught not to bond together. According to hooks (2000), Black women need to unlearn this. This unlearning of “internalized sexism/racism” is pivotal to creating political solidarity among Black women.

Collins’ Afro-centric Feminist epistemology reflects elements of both women and African-Americans’ epistemologies. This means being a part of these groups and yet, at the same time, standing apart from both groups (Collins, 1991). hooks (2000) believes this insider-outsider position is essential to Black women’s consciousness. Collins (1991) acknowledges the diverse experiences of oppression among Black women given their varied insider-outsider positions. This diversity of experiences informs her epistemology.

Collins’ four basic tenets of Afro-centric Feminist epistemology (AFE) are: a) concrete experience as a criterion of meaning; b) use of dialogue to assess knowledge claims; c) ethics of caring - talk from the heart (expression, emotions and empathy); and d) ethics of personal accountability. These four tenets are interrelated and work together to form an AFE.

Concrete experience as a criterion of meaning

In this dimension of an AFE, Collins suggests that there are two ways of knowing – knowledge and wisdom. The distinction between the two is based on lived experience. Knowledge is information not experienced whereby wisdom is knowledge gain through experience. Those who have lived experiences of a situation are considered to have more credibility than those who have no direct

personal experience. Related to the importance of lived experience is the use of practical images, narratives and stories that are representative of the lived experiences of Black American women. These forms of knowledge allow for subjectivity between women, reside in the women (not higher authorities) and are experienced directly in the world, not through abstractions (Collins, 1991). Within her narrative method, these stories or experiences are told and trusted by the communities of Black women. Concrete experiences of self-definitions are valued and validated within various institutions of black women's lives – their centrality in the family, the church and other places where people congregate.

Use of dialogue to assess knowledge claims

The process of validating and assessing claims to knowledge is done through the use of dialogue. Dialogue here is equal and mutual engagement between two active individuals (hold subject positions)– the speaker and listener who are both members in the community. This is in contrast to euro-centric masculinist epistemology of active subject to a passive object (Collins, 1990), in which there is no dialogue.

The primary epistemological assumption supporting the use of dialogue in determining knowledge claims is the connectedness to others (Collins, 1991). This connection with others is part of a traditional African holistic worldview which seeks out harmony. This connectedness is an important aspect of the knowledge validation process from an AFE. In this process, people actively engage in seeking connections with others and become more human and empowered within the context of a community (Collins, 1991). This is in contrast to euro-centric masculinist epistemology of separation or isolation to create knowledge within research settings such as the laboratory, and within academic spaces isolated from communities.

The ethics of caring - talking with the heart

A third tenet of an AFE epistemology is the ethics of care or talking with the heart, which involves three related dimensions: personal expressiveness, emotions, and empathy. All three dimensions are pivotal to the AFE knowledge validation process (Collins, 1991).

The first dimension of the ethics of care is the importance of the uniqueness of each individual. Based in African humanism, each person is seen as a distinct and valued being (Collins, 1991). One example of this value is illustrated in black women quilters who place vibrant patterns and colours next to each other in a quilt. The individual differences within patterns are seen as enriching the entire quilt, not competing against each other (Collins, 1991).

The second dimension is the legitimacy of emotions in dialogue. To display emotion in dialogue, means that the speaker is invested in the validity of the argument (Collins, 1991). In AFE, there is no need to separate emotions from intellect to advance and assess knowledge. This is in contrast to euro-centric male epistemology which favours dispassionate and objective knowledge. In this epistemology, knowledge can only be gained if the knower excludes emotion and feelings. This separation of emotions from intellect supposedly avoids bias in acquiring knowledge through a scientific research process. The third dimension is the development of the capacity for empathy. Collins (1991) claims the capacity for empathy is important not only for the knower (oppressed) to extend to others, but to believe in others' capacity for empathy. Collins acknowledges that the ethics of care may be part of women's experiences and this supports the AFE of connection in which "truth" emerges through care (Collins, 1991).

The ethics of personal accountability

The last of AFE's proposed ways to assess a person's knowledge claims is, at the same time, to evaluate the person's character, values, and ethics. This is done by asking for information on the individual's values and daily life experiences. In relating their concrete experiences, individuals reveal their point of view, what they hold important, how they relate to people and the derived meanings of these experiences. All of these qualities, point to the overall character of the person, their relationships to others and to the actions they take in everyday life and in acquiring knowledge. According to Collins (1991), this accountability is essential to assess the knowledge claims of any person. These major tenets of AFE provide the basis to shape a Critical Disability Studies epistemology to which I now turn.

III: The shaping of a critical disability studies epistemology

In this section I discuss how I have shaped a CDS epistemology to teach CDS within the Physical Therapy program at the University of Toronto. The CDSE I articulate and use is underpinned by many of the views expressed by Collins (1991) and hooks (2000) and disability justice activists (Berne, 2015; Mingus, 2011). Collins (1991) suggests that subjugated knowledge is produced by groups who are marginalized or othered by dominant groups. As disabled people have been (and still are) excluded from mainstream society, they are a group that have produced their own subjugated knowledge.

As mentioned earlier in the chapter, I am not conflating gender, race and disability- they are not interchangeable. I agree with Collins and hooks in their observation that there are many sites of oppression that are interlocked or connected, as they are produced

by an overarching historical system of oppression. Disability as an axis of oppression shares some similarities with race and gender, but the expression of privilege and penalty of disability will be varied, and the meanings of privilege and penalty will be influenced by the particulars of the disability/difference and many other axes of oppression (race, gender, class, age, sexual orientation, indigenous identity, rural/urban, nation state, etc). This acknowledgement of how multiple social locations may be seen as interlocking oppressions is the basis for current understandings of intersectionality. Given this, intersectionality (Hankivsky, 2014) is an important concept and way of thinking that physiotherapists need to embrace. Earlier in this chapter I mentioned that the Social Determinants of Health has helped the health professions to turn towards the social. The SDH is an important first step in understanding an intersectional approach and could be implemented within PT curricula. In addition, writings on Disability Justice emphasize this understanding of intersectionality (Berne, 2015; Mingus, 2011).

In what follows, I draw on the four tenets of AFE to inform my formulation of a CDSE. I will elaborate on how each “fits” or is consistent or not consistent with current disabled scholars’ thinking of disability. I bring into this conversation disabled scholars who are speaking about some of the same issues – oppression, intersectionality and disability social justice.

“Lived” experiences as an essential criterion of meaning

The importance of concrete lived experience is core or fundamental to any CDSE, and I have shown that this lived experience is essential to an AFE. The lived or embodied experiences of disabled people provide the foundation for critical reflection and analysis. This lived or embodied experience means that individuals are able to

critically articulate how social structures/ institutions (e.g. policies, rules) have impacted their lives (Williams, 1998). However, domination related to disability can make it difficult for disabled people to “see” and articulate how institutions and practices affect their daily lives.

Disabled people’s oppression has often been labelled ableism. Ableism is a system of oppression produced by the dominant abled-bodied majority view (Campbell, 2008). This view is reflected in physical/social environments , practices and behaviours taken for granted. Disabled people are excluded in society if the physical environment is constructed in such a way that it poses barriers to access, e.g. barriers to wheelchair users. Social practices of watching a movie in a theatre demand that all who attend can see and hear the movie. This would exclude those identified as deaf and/or blind. Taken for granted interactional practices, such as how one greets another person by saying hello and looking directly at them, assumes that everyone can interact in this way.

Ableism as a system of oppression is based on a normal/abnormal dichotomy. Like sexism and racism, it has its roots within a western dichotomous system of thinking. Even within a more current western culture of hybridity and diversity, this dichotomous mode of thinking of disability still prevails. The concept of the normal and its construction has been fully articulated elsewhere (Davis, 1995), and is summarized briefly here. The idea of the “norm” was spurred by Eugenics and the population movement. Measures such as weight, height, limb length and so on, were seen to be distributed along a “bell” shape curve, with the mean or most frequently observed measurements forming the centre point of this curve. This bell shaped curve has two endpoints that indicate amounts of the trait/measure that is lesser or greater than the average for the population. Both would be seen as departures from the average measure. This posed a problem for eugenicists

as traits such as intelligence or heights that were greater than the average would be seen as departures from the norm, albeit, in a negative way. To deal with these situations, Francis Galton, created the concept of quartiles (Davis, 1995). The bell curve distribution of a trait was then segmented into quartiles, and he substituted the idea of ranking. This meant a rank order from lowest (first) to the second and third quartiles encompassing the majority of the area under the centre part of the bell curve. The highest quartile is at the upper end of the curve. This use of ranked quartiles has allowed eugenicists to say that those who were very tall in height – fourth quartiles) possessed a desirable amount of the trait. At the other end of the curve, those whose traits were in the first quartile were seen as possessing insufficient amount of the trait (e.g. intelligence, height, weight) and were seen as deviating from normal and thus devalued (Davis, 1995).

This arbitrary definition of normal contributes to the normal/abnormal dichotomous thinking in western science that continues to be propagated by institutions that promote this particular way of being and doing things. For example, in medicine and rehabilitation, there are specific “normal” ways to move around in the world. This usually involves walking upright as the standard (Gibson, 2016). This is an ableist view of moving around. This dominant assumption of standing upright has implications – for example, how physical environments are structured (stairs), how space to get around is configured, and how clothes are designed and produced.

Disabled people who attend healthcare institutions for treatment risk becoming socialized to see the world in this way and to believe this is the correct way. For example, the idea that upright mobility is only way they should move. Given this, disabled persons may spend much time learning how to move in this way and may forego any other options for mobility. This is an ableist view of mobility.

If a person comes to learn and believe that upright mobility is the only or preferred way to move in the world, one can say that the person has internalized an ableist perspective on mobility. The disabled person's internalized ableism is a form of oppression inculcated from the dominant abled bodied majority. This internalized ableism is widespread – it can relate to every facet of everyday life, such as work, school, relationships, family and social etiquette. Similar to Black women, disabled people may need to unlearn the internalized ableism, to reflect, question and challenge it and to speak out about how they believe they should be in the world based on their experiences (Campbell, 2009).

Use of dialogue to assess knowledge claims

It is essential for a CDSE that disabled people speak and share their experiences with other disabled people. The importance of dialogue to assess knowledge claims was highlighted in AFE. Historically, disabled children had been segregated in schools, and had lived in rehabilitation treatment centres, especially in urban centres. It was thought that this separation from mainstream society would help disabled children to learn and focus on normalized ways of being and doing. While the situation has changed today, in that disabled children are not isolated from others, the emphasis during treatment is still to learn how to move and act in normalized ways. However, clustering together in rehabilitation spaces has had, in many cases, unanticipated effects. By being together, disabled children also can share their stories and their experiences. Individuals speaking to each other may learn that their differences are not individual, are socially produced and in some cases, learn how to resist these normalizing processes (Yoshida, Shanouda & Ellis, 2014).

Dialogue is also important for the teaching of others who do not have this direct lived experience. Disability Justice scholar

Patti Berne (2015) talks about sustainability, which means that disabled people's teachings and experiences are the critical guide to a disability justice movement. For physiotherapists, this means seeking out and acknowledging the legitimacy of disabled person's experiences and how this knowledge is important to our collective practice, teaching and research. Disabled people need to be involved in the teaching of their own lives to non-disabled people (Linton, 1998). This leadership is important as disabled people, disabled scholars and disabled physiotherapists know how the system impacts their daily lives (Berne, 2015). In teaching CDS using a CDSE, this means using first person narratives (in for example, print, video or in person) to impart knowledge. It also means including disabled scholars' writings as well. Dialogue needs to be set up between the disabled person/teacher and non-disabled student/learner in an environment that is safe and encourages participation.

The ethics of caring - "talking from the heart"

A CDSE needs to emphasize the importance of passionate dialogue, or speaking from or with the heart, as part of the process to assess knowledge claims. The first dimension of speaking with the heart involves the reflection and expression of each unique disabled person. Each disabled person is valued as they are and who they are within an approach acknowledging that all people are worthy (Berne, 2015). This valuing of each disabled person and his/her/their individual self(ves) expression(s) is important and is exemplified by the disabled community's efforts to engage in disability social justice related to access. The disability social justice notion of access emphasizes moving away from accessibility as an individual and independence perspective to a view of access as collective and interdependent action (Mingus, 2011). This means the

group acknowledges every person's uniqueness as well as supporting each other to achieve access. For Mingus (2011, p. 1), accessibility is important because "It is the concrete resistance to the isolation of disabled people".

The importance of emotionality in dialogue is related to this self-expression. Emotionality conveys the individual's life world to others in a more complete, complex and nuanced way that resonates with disabled and non-disabled people. Finally, a CDSE requires empathy. Empathy requires the willingness of the knower to continuously listen and learn from disabled people themselves. This continuous learning is important for both disabled and non-disabled people. For disabled people, it is not enough to know one's own experiences, but in addition to learn from other disabled people's experiences and needs. For non-disabled people, including myself, there is always something to learn from my disabled colleagues both in the community and in academia.

The ethics of personal accountability - one's relationship to disability

In evaluating people's knowledge from a CDSE, it is important to assess their relationships to disability (O'Toole, 2013). This information gives the listener important knowledge about the knower. From a CDSE, one would question: who are the relationship(s) with? What is the type of relationship? Is it with a professional service organization for a disability or a disability rights organization? Is it led by disabled people? What orientation to disability does the knower claim – Individual, Medical, Social or Disability rights? Are the relationships temporary, enduring, reciprocal and/or equitable in nature in relation to issues of power and control? Do the relationships embrace everyday knowledge and/or professional knowledge? All of these questions will provide the listener with a way to

assess an individual's character, values and ethics and ultimately to assess their knowledge claims related to disability (Collins, 1991).

Conclusion

I have presented a CDSE that has supported my teaching CDS within the Department of Physical Therapy at the University of Toronto. I have used AFE as articulated by Collins, reinforced by hooks, as the basis for this alternative CDS epistemology. CDSE emphasizes a number of important principles: the critical reflection of lived experiences, active dialogue related to connectedness to others and the community, emotionality and empathy as investment in knowledge and accountability related to one's relationship(s) to disability. These principles of a CDSE are situated within a system of interlocking oppressions which can constrain action and opportunities.

What is the way forward for the future of physiotherapy relative to CDS? CDSE provides an alternative and critical epistemology that brings in embodied knowledge of disabled people to better inform physiotherapists in teaching, research, and practice. Understanding the impact of the health and social systems on disabled people will assist physiotherapists to be allies (disability justice) in supporting and advocating with disabled people within the context of complex health care systems. For example, a shift away from an abelist notion of independence (being physically self sufficient) to encompassing an interdependent view of physical therapy practice (embracing access, mixed abilities and helping others) would mean challenging the exclusive importance of upright walking to embracing a more diverse way(s) of mobility based on a person's need in different spheres of life. Given the intersecting issues of racism, sexism, and poverty with disability, physiotherapists would need to consider these issues as well in working with

people to develop desired forms of mobility. In this way, physiotherapists will be supporting these justice movements as well. We need to incorporate a critical epistemology that will support the continuing evolution of our critical, reflexive and action-oriented profession. In this way, CDSE provides the basis for socially just physiotherapy practices that will support equitable health services for all.

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