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# The integration of self-determination theory: Supplementing preceding and future models of disability

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## **Abstract**

Disability studies continues to grow as an emerging area of practice and theoretical research, branching out into sundry professions and frameworks. This expansion is leading to perpetual discussion of the more prominent individual (medical) and social models of disability as well as the development of more inconspicuous models. This paper reviews the dominant epistemologies attached to these models of disability with the support of an authentic case vignette from the author's social work practice. It is argued that the supplementation and immersion of self-determination theory in established and future models of disability will enhance the models' applicability to professional practice and better reflect the individual's self. The integration of self-determination theory to models of disability is presented in multiple diagrams.

Keywords: disability, epistemology, self-determination, social work, models of disability

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## **Introduction**

Disability studies has been an emerging area of research in Western European academia since the mid-1970s (Meekosha & Shuttleworth, 2009). Its dominant epistemologies and models originated from members of the disability community itself, highlighting its grassroots spirit. Disability scholars, who were often living with disabilities themselves, began to conceptualize and raise awareness of the lived experiences of persons living with disabilities (Ferguson & Nusbaum, 2012). Disability research raised predominant concerns within the disability community and naturally began to combine a common set of core ideas (Ferguson & Nusbaum, 2012). The existing focus of disability research appears to be weighted on opposite ends of a spectrum. On one end of the spectrum is medical research to "fix" bodily impairments, while on the other end is policy research to prompt greater accessibility to resources and services (Pfeiffer, 2001). These two spectrums are regularly defined as the individual (medical) model and the social model of disability (Oliver, 2004). Researchers often argue that the two models conflict with one another and as will be discussed, are conflictual in the research community. New models have been introduced in disability studies with partial success either to find a balance

between the two models or offer an alternative approach. Nonetheless, the adoption of alternate models has been sporadic and unpopular, until the introduction of Rosi Braidotti's (2013) critical posthumanism. Some disability scholars have suggested a link between disability and posthumanism, asserting disability as the quintessential example of the posthuman condition (Dolezal, 2017; Goodley, Lawthom, & Cole, 2014).

The goal of this paper is to further develop the discussion of alternate disability models between scholars and the disability community by considering the epistemological underpinnings for disability studies. I will do this by introducing a case vignette from social work practice that will inform discussion around the dominant individual (medical) and social models of disability from a historical perspective, new models that have appeared within the disability community, and self-determination as a complementary framework for all models. This paper is organized in five sections: (1) a case vignette, (2) a discussion of epistemological issues in disability research from a historical perspective, (3) the presentation of alternative perspectives in disability research, (4) the sharing of supplementary perspectives in disability studies, and (5) the coverage of future areas of research. The brief case vignette that is presented is from my own professional social work practice and is shared to assist in facilitating some examples within the paper.

### **Case Vignette**

During my social work practice at a pediatric hospital, I worked with an individual named Jenn (age 13 years), whose name has been changed for anonymity purposes. Jenn and her mother were initially referred for social work support because Jenn wanted support regarding effective strategies for pain management and her mother desired help for coping with a conflictual divorce. I worked with Jenn and her mother for approximately two years and observed Jenn's needs growing over time. At our initial meeting, I learned about the strengths and complexities of this family. Over the two years that I worked with them Jenn dealt with several interdependent challenges in her familial environment and with her mental, biological, and social health. For example, her parents were in a conflictual divorce that required family court intervention. Jenn also disclosed a history of sexual abuse, which required further child welfare and police involvement. In addition, her bodily pain was intensifying. Jenn's illness went from a level of manageable pain with which she was still able to teach swimming lessons, to that of sporadic uncontrollable pain, where she required the use of a walker.

Jenn had approximately six medical specialists that she saw on a monthly to yearly basis, a multitude of allied health professionals, and her family physician. She also attended a yearly camp for children and youth with autoimmune conditions. The working diagnosis for her illness was fibromyalgia, but not all of her symptoms were consistent with that condition. After approximately one year, Jenn revealed to her mother that she was transgender (female to male), and wanted to be referred as Chris using the "he/him" pronoun. Although Chris' family and health professionals were supportive, his social health worsened. After being unable to continue going to his school, he ended up registering in a private school for children and youth with special needs. Even though this particular school was designed to welcome Chris regardless of present challenges, that is not always the case with educational institutions (Graham & Iannacci, 2013).

Chris' story is being shared because it highlights the complexity of people's needs. All Chris' needs were interdependent and connected—it was infeasible to separate them. The risk

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with attempting to stratify them is the loss of some context and understanding of the whole picture. As I continue with this discussion, I will refer to Chris' case to ameliorate the connection between theory and practice.

## **Issues of Epistemology in Disability Research from a Historical Perspective**

### **Individual (Medical) Model of Disability**

McClimens (2003) asked, "how do we know anything about disability?" (p. 42). Perhaps we can take this question one step further and ask how we know disability exists? What we know and what we consider to be knowledge is always from a certain perspective and for a certain purpose (Fang Law & Ramos, 2017). Before something can be asserted about disability, we must abandon the notion that there is only one perspective and that it is not political. Can something be asserted about disability? From a positivist and postpositivist epistemology it can. Positivism was the dominant epistemological underpinning of disability research in Western Europe in the 1700s (Oliver, 2004). The positivist paradigm's ontological assumption is that there is one reality that can be observed and measured in an objective way (Chilsa, 2012). The positivist epistemology is referred to as both the individual and medical model of disability, and it replaced the moral/religious model in the Enlightenment Period (Bingham & Green, 2016). In both the moral and individual (medical) models, disability is associated with impairment or bodily difference (Bingham & Green, 2016). In the moral model, impairment was viewed as a moral failing or as the result of divine punishment for previous behaviour. The individual (medical) model shifted this perspective of impairment being a moral failing to a problem. This inspired medical professionals to diagnose and treat impairments in hopes of helping the individual to return or get as close to "normal" as possible. The individual (medical) model focuses on defining, grading, and categorizing conditions and impairments (Hughes, 2013).

In Chris' case, diagnosing and treating were the major focus of the medical work. As explained previously, his working diagnosis was fibromyalgia but that did not fit with all his symptoms. Regardless, there is currently no known cure for chronic pain conditions; however, medical professionals and his family were desperate to find a diagnosis, resulting in continued medical visits and tests. According to Oliver (2004), the medicalization of disability gives physicians power and leaves people with disabilities powerless. If individuals with disabilities are pathologized whereby the impairment is deemed to need fixing, the physician becomes regarded as an expert of the individual's body. This imbalance creates a dynamic between the physician and person with the disability that reflects power and powerless.

### **Social Model of Disability**

In the early 1980s, Mike Oliver, a disability rights campaigner, individual, and scholar, introduced an alternate perspective to the individual (medical) model, which is currently referred to as the social model of disability. Oliver stated that the social model of disability is, "a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environment impose limitations upon certain categories of people" (Oliver, 1981, p. 28). There are two key terms in the social model: (1) impairment, which is a long-term characteristic of an individual that affects their body, mind, or senses; and (2) disability, which is a result of exclusion because of the barriers society puts in the way (Hughes, 2013). For

example, the dominant discourse around being transgender was that it was a treatable disease, whereas now, there has been a shift through human rights initiatives to discredit that opinion and move toward embracing diversity and awareness (Robertson & Doyle-Jones, 2015). Nevertheless, transgender medical services still subscribe to the medical model. Medical professionals are persistent in wanting to identify, categorize, diagnose, and set eligibility criteria for sex reassignment surgery. In the past, some teens were psychiatrically hospitalized for treatment of gender identity disorder and made to wear dresses, even though wearing dresses is not necessarily a characteristic of being a woman (Pazos, 1999). This reflects how femaleness and femininity were constructed within that paradigm.

The social model of disability stems from a transformative paradigm, its purpose is to destroy myths and empower people to change society radically (Chilsa, 2012). Contrary to the positivist paradigm, an ontological assumption of the transformative paradigm is that multiple realities are shaped by human rights and disability values (Chilsa, 2012). The medical model is configured in such a way that it never fails. If the medical community does not have a remedy or solution for something, its logic is to invest more resources into researching and elucidating one. It does not reduce the value of medical intervention or treatment but instead strives to focus on developing or identifying solutions to the disadvantages or issues that many people experience (Hughes, 2013). Oliver's hope for the social model at the time of its introduction was that it would accurately reflect the experience of members of the disability community and inform political movements (Oliver, 1990). It was successful in that regard as the social model of disability was promoted in a range of training and organizations, played a role in the Disability Movement, and was adopted by the British Council of Organisations of Disabled People (BCODP) (Oliver, 2004).

### **Paradigm Shift in Disability Approaches**

In 2006, the United Nations Human Rights Office of the High Commissioner adopted The Convention on the Rights of Persons with Disabilities to signal a paradigm shift from the traditional individual (medical) model approach to disability to one based on human rights (UNHR, 2018). The discourse began to focus on accessibility to education, employment, independent living, participation in community, and social justice (UNHR, 2018). Similarly, the World Health Organization's definition of limitation and disability are consistent with that in the social model as well, identifying disability as "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" (WHO, 2018, 1). The social work profession has also taken initiative to integrate disability within a critical and social justice lens. In 1993, The Canadian Association of Social Work Education (CASWE) founded the "Persons with Disabilities Caucus" to address the lack of social work education and research relating to persons with disabilities in Canadian social work programs (Carter, Hanes, & MacDonald, 2012). CASWE accreditation standards were eventually established from this initiative and disability was included as a guiding principle for accreditation of social work education programs within a diversity and social justice framework (CASWE, 2014).

These models of disability are applicable to Chris' situation. For example, he experienced inaccessibility to public education. He did not fit into the standardized education system and he required flexibility and accommodation. In addition, his classes were physically far apart, amplifying his pain when travelling to class, and he began failing his classes due to missed time because of medical appointments. Bullying was not an issue at his school and socialization at

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school was a strength. However, due to the aforementioned barriers and constraints of the public-school system, his disability was reinforced. This example highlights how the setup of the structural system exacerbated Chris' disability, rather than his impairment.

### **Alternative Perspectives in Disability Research**

Some scholars, along with Oliver, insist that diversity in disability models are strengthening and enriching (Levitt, 2017; Oliver, 1996; Smart & Smart, 2006). Multiple models can make a greater contribution to our understanding than a single perspective. Alternative models have been suggested but there appears to be apprehension in the literature regarding their adoption and application. Some of these models include the multifactorial perspective of disability (e.g., physiological, environment, social, cognitive, and emotional factors) (Johnston, 1997), the affirmative model (i.e. positive identity encompassing impairment) (Swain & French, 2000), the environmental model (Smart & Smart, 2006), and the Bolt model (i.e., the happiness-related model) (Bolt, 2015). One of the more recent suggestions is the active model, which focuses on the impact of the actions of disabled persons on disability itself (Levitt, 2017). These actions include both individual and collection actions.

There has been a lot of discussion about the social model and alternative models of disability (Oliver, 2013). Oliver published a commentary in 2013 titled "The Social Model of Disability: Thirty Years On" in *Disability & Society*, calling on researchers to either "reinvigorate the social model or replace it with something else" and pressed that the talking about them should stop (p. 1025). Most approaches to expand or reinvigorate the social model are theoretical and have not been translated into practice. Oliver explains in his commentary that initially the objective of the social model of disability was to emphasize impairment and disability in the social context to protect benefits and services. However, he states that due to the recent economic climate in the United Kingdom, policy is further dividing the population of people with disabilities into those who are severely impaired (deserving) and those who are not (Oliver, 2013, p. 1026). Individuals are being assessed and categorized into moderate, substantial, and critical categories, with most services being offered to those in the critical category. This is occurring similarly in Canada. For example, in Ontario there is a program in place to support new mothers with physical disabilities named the *Direct Funding Program*. This program finances the offering of self-directed attendant services to qualified mothers and supports the hiring, training, and paying of their attendants (Ocampo, 2001). The mother directs the attendant on what they would like them to do and describes how to care for the baby, acting like a surrogate for the mother. However, this is a restricted program—only those mothers with the most "severely physical" impairments have access to the funding.

Dichotomizing and categorizing individuals is problematic because it does not account for the individuals' needs as a whole. In terms of Chris' disability, he was at the point that he needed to use a walker but that is not considered a severe impairment in the context of the *Direct Funding Program*. Nevertheless, the complexities of his issues at the time were pronounced. Under the terms of the *Direct Funding Program*, a mother may have a full-time family member living with her or an older child who could help and thus does not require the service due to her particular circumstances. However, another woman may be a single parent with no support, and that program's support may make a difference between child welfare involvement or not. This is where multiple contingency thinking is relevant.

## **Posthumanism**

Disability research appears to be moving in the direction of posthumanism. Posthumanism criticizes the humanist ideal of man as the universal representative of what a human being is (Brandotti, 2016). Brandotti uses the example of the Vitruvian Man as the ideal human. He is white, able-bodied, masculine, and European. When people deviate from this image, we begin to question if they are less than human. Prominent disability scholars like Dan Goodley agree that “human” may be an outdated phenomenon and contends that disability is a quintessential example of posthumanism (Goodley, 2014). This is because like posthumanism, disability breaches the traditional definition of human and is always in conflict with the idea of what the ideal human is (Goodley, 2014). Posthumanism decenters man as the measure of all things, acknowledging its interdependence on other humans, technology, and the environment (Dolezal, 2017). As a result, individuals have fluid and multiple identities (Brandotti, 2016). This is not far removed from disability whose members sometimes rely on others and assisted living technology for support.

Posthumanism is not in conflict with the social model of disability and has potential to tackle ableism. A women’s studies scholar, Dolezal, (2017) wrote about a posthumanist example that discussed athlete and model, Aimee Mullins. Mullins is Paralympic athlete, model, and actress in the United States. She was born with a medical condition that required both of her lower legs be amputated. Mullins later became famous for her 12 pairs of legs and presented a Technology, Entertainment, Design (TED) talk wherein she introduced her many legs. Her legs are various lengths depending on the heels she is wearing and she has different variations. Dolezal (2017) argues that Mullins represents posthuman embodiment, her body is full of possibility and enhanced capabilities. On the other hand, this example demonstrates the use of technology being used to bring Mullins nearer to the “normal” body. She argues that the ideal able-bodied person is still preferable in mainstream society (Dolezal, 2017).

Chris seemed to be very heartened when he found role models like himself. Each summer, Chris went to a week-long camp for children and youth with autoimmune diseases. After the first summer he recalled how shocked he was that the counsellors and other youth had been diagnosed with fibromyalgia and lived with chronic pain as well. Mullins plays a similar role in terms of representation within the disability community. It is unclear if individuals living with disabilities see her as an example.

## **Supplementary Perspectives to Disability Research**

### **Self-Determination**

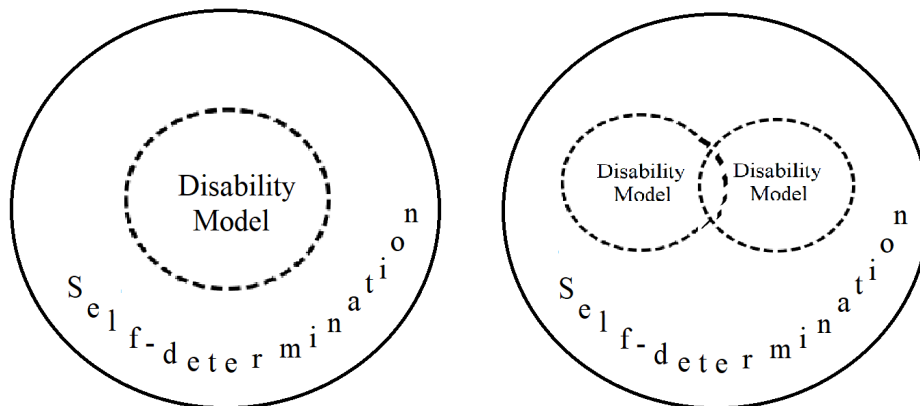
In this section, I offer my own thoughts on how to best supplement the dominant disability models and the newer proposed models of disability. Something missing from the existing models, or which is not as prominent as what was previously described, is the questioning of dichotomous modes of thinking. An approach to this frame of questioning is to consider the individual’s self-determination and subjectivity. In disability studies, there is a dichotomy of disabled/not-disabled and the “disabled” get further categorized into subgroups. The individual (medical) model faults the problem as impairment and the social model faults the problem as society. The diversity and intersectionality of the group are missing from this discussion because as the context and subjectivity changes for the individual so can the category

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criteria and whether the individual is even still in the “disabled” group. Chris’ relationship with his peers is an example of this.

During the years in which Chris’ health was declining he began to spend less time with his friends. His mother became concerned that he was becoming antisocial and blamed chronic pain as the culprit of his withdrawal; his physicians became concerned and worried that he was becoming depressed; and I became concerned that he was not getting enough opportunities to socialize. These are three alternative responses to Chris spending less time with his friends. Chris’ perspective was missing. After discussing it with him, he expressed that he was not upset or concerned about spending less time with friends. In terms of socialization, he was getting his needs met through family and the little time he was spending with his friends during his time at school. When youth begin withdrawing from friends and activities it is sometimes a sign of concern, but this is not the case for all youth. The barrier with overarching disability models and categorization of disability is that the individuals’ context can get lost. Normal is argued to be conceptualized and predisposed toward the needs and interests of the privileged (Sprague & Hayes, 2000); therefore, caution should be applied when implying what someone’s behavior should look like.

The two diagrams in Figure 1 are proposed as alternatives to the siloed models presented thus far in disability studies. There is agreement with Oliver that diversity among models is essential to understanding the full scope of needs in the disability community. However, there need to be precautions to ensure that some individuals are not assimilated into the experiences of the dominant group. Specifically, there must be freedom allowed for individuals to move fluidly throughout categories, reject categories, and adopt categories.



*Figure 1 – There are two diagrams. The first, located on the left, is a perforated circle with “Disability Model” written in the middle. It is engrossed by a larger circle labelled “Self-determination.” The diagram on the right is identical except it has two perforated circles in the middle with “Disability Model” written in both of them. The two middle perforated circles overlap with one another.*

The two diagrams in Figure 1 are similar, except the diagram on the right shows an ability to have more than one model of disability. The idea illustrated within the diagrams is that disability model(s) are located in the middle and then engrossed by the individual’s self-determination. The model(s)’ circles are broken to illustrate the freedom to move in and out and to reject the notion of rigid categories. It is

possible to use multiple disability models if appropriate in context; these two could even be the individual/medical and social models. Importantly, the individual's self-determination never gets lost in the perspective.

Self-determination theory posits two broad types of motivated behavior: those consciously chosen in the service of intrinsic or extrinsic needs and those that are not consciously chosen (Deci & Ryan, 2012). Self-determined behavior is constructed from the individual's and their environment's inputs and are selected based on the person's needs (Deci & Ryan, 2012). In contrast, mindless or automated behaviors are conditioned, and the behavior is automatic (Deci & Ryan, 2012). Examples could be playing with your hair or blowing bubbles with gum. These behaviors are functional and linked to specific needs (Deci & Ryan, 2012).

Discussion around self-determination does not appear to have a large presence in disabilities studies. It seems to be cited and applied more in the field of education pertaining to children and youth with learning and intellectual disabilities, often for the purpose of investigating whether self-determination skills should be taught in school (Marks, 2008; Russo Jameson, 2007; Zhang, 2001). One study by Stoner, Angell, House, and Goins (2006) investigated the perceptions of 12 adults living with a congenital physical disability (e.g., spina bifida, cerebral palsy). They used semi-structured interviews to ask participants how they defined self-determination, how it is important, and if the participants could identify any barriers. Their findings suggested that even though the participants received little to no formal instruction, they exhibited high levels of self-determination. Support from families, individuals, and support networks was an important theme that emerged from the stories regarding facilitators of self-determination. When identifying facilitators of self-determination, one participant stated that, "Self-determination to me is ... that it was laid out for me, it all started at home. I mean, with, there was a foundation that was laid for me. They've [participant's parents] allowed me to grow and to learn on my own (Stoner et al., 2006, p. 13).

Interestingly, when asked about barriers to self-determination, the participants named both impairment and societal factors as impediments. All participants named their physical impairments as a barrier to self-determination. For example, one participant expressed that it takes them several hours to brush their teeth and they will never be able to tie their shoes (p. 15).

The societal barriers that were mentioned included financial assistance, accessibility barriers, and discrimination. The negative attitudes of others were also perceived as a barrier to self-determination. The interviews illustrate differences in how individuals with disabilities experience self-determination and barriers, as well as how personal experiences can shape individual perspectives. Simultaneously, it is apparent that self-determination is affected by interpersonal and social-structural relationships, and that the "self" is socially constructed (Sprague & Hayes, 2000). The ongoing development of the self is another example why the proposed disability models are broken lines making up the circles in the middle of the diagrams, because the process is ongoing.

### **Areas for Further Research**

In response to Oliver's (2013) commentary regarding the reinvigoration or replacement of the social model of disability, Levitt (2017) had further questions of his own. Levitt also wondered how the social model could be implemented, aside from it being used as a practical tool. He speculated what the primary goals of the social model should be. Before brainstorming ideas for how to use the social model



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in multiple context, perhaps it is beneficial to apply it well in a practical way. Similar qualitative studies that Stoner et al. (2006) completed with persons living with physical disabilities may be beneficial in learning how individuals construct their own reality and their “self.” It would also be worthwhile to interview family members and service providers, as these groups also impact how the individual constructs their experience with disability. Collecting visual and textual data is another approach to explore how disability gets constructed. For example, reviewing material on the *Direct Funding Program* or another social service program would inform some of these questions.

### **Conclusion**

The objectives of this paper were to (1) introduce the dominant models in disability studies and alternative models of disability and (2) to discuss ways to supplement current social work practice to better support the disability population. Positivism and the social model of disability from historical perspectives were reviewed to illustrate how the dominant individual (medical) and social models of disability emerged. Examples of alternate models that have been introduced in the literature but had sporadic support and minor acceptance were discussed. Oliver’s (2013) call for new ideas regarding the social model of disability in the *Journal of Disability and Society* appears to have ignited a discussion on how to improve the status quo with alternative models of disability (Bolt, 2015; Johnston, 1997; Levitt, 2017). Instead of retiring disability models, this paper proposed that they be supplemented with self-determination theory.

The combination of the steady increase in the number of persons living with disabilities and the continued difficulty regarding accessible social services programs are two key reasons for why facilitating and participating in discussions around models of disability is crucial to social work practice. Applying the disability models and self-determination theory to the case vignette illustrated how social work perceptions and the conceptualization of disability inform practice with persons living with disabilities. In addition, the respect and promotion of self-determination with clients is a social work ethical standard and responsibility in both the National Association of Social Workers (2008) and the Canadian Association of Social Workers (2005). Applying disability models in social work practice within the context of self-determination is consistent with the profession’s code of ethics and respectful of the clients and families social workers support. However, social workers often adopt the individual (medical) models of disability (Mackelprang, 2010), indicated that further work in this area is needed. There is optimism that the future of disability studies is heading toward a plethora of innovative ideas and strategies to better serve those individuals living with a disability, which can ultimately be applied to the social work profession.

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