„CZŁOWIEK – NIEPEŁNOSPRAWNOŚĆ – SPOŁECZEŃSTWO”
CNS nr 1(31) 2016, 5–23

ISSN 1734-5537
DOI: 10.5604/17345537.1209242

ARTYKUŁY I ROZPRAWY

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DISABILITY STUDIES: A VIEW FROM THE HUMANITIES

Disability Studies[1)]

Disability Studies is an interdisciplinary academic endeavor that analyzes disability and the lived experiences of people with disabilities from the perspective of the humanities, social sciences, and arts, not the medical or applied fields (such as rehabilitation science or other related fields). Disability Studies has its political and intellectual roots in the disability rights movement that began in the United States and the United Kingdom in the mid-twentieth-century and, by the turn of the twenty-first century, expanded to include other countries such as Canada and Australia, various countries in Europe and South America, and countries in South and East Asia. One of the basic tenets held by disability studies researchers is that “disability” extends beyond individual bodies. Disability is not merely something that an individual has (I have cerebral palsy) or is (I am a paraplegic). Disability is created socially by built environments, cultures, and social norms that devalue, stigmatize, segregate, or discriminate against people who are considered “abnormal.” Scholars of Disability Studies have labeled their focus on the interactions among disabled people and the world around them the “social model” of disability, which they define in opposition to an older, well-entrenched “medical model” of disability that sees it in more negative and individualizing terms, as a deficit or defect that must be fixed, cured, or eliminated in order for an individual to function “normally” in society.

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[1)] Portions of this article have been revised and reprinted with permission from: Michael Rembis, “Disability Studies,” *International Encyclopedia of Rehabilitation*. J.H. Stone, M. Blouin, eds. (Center for International Rehabilitation Research Information and Exchange, 2010; revised 2015) http://cirrie.buffalo.edu/encyclopedia/article.php?id=281&language=en

The institutional roots of Disability Studies can be traced to academics working in the United States during the early 1980s. In 1982, the Western Social Science Association created the Section for the Study of Chronic Illness, Impairment, and Disability, which became its own separate organization in 1984. In October 1986, the Board of Directors of the new organization renamed it the Society for Disability Studies (SDS). That same year, Irving K. Zola, university professor and first president of SDS, changed the name of the organization's main publication, the *Disability and Chronic Disease Newsletter,* to the *Disability Studies Quarterly* (DSQ). The DSQ grew from its humble beginnings as a newsletter in the early 1980s to one of the most widely known and well-respected peer-reviewed academic journals in the field of disability studies by the turn of the twenty-first century. By 2015, the DSQ was publishing dozens of research articles, essays, reviews, and creative pieces each year, which it made available through an "open access" online journal produced in cooperation with the Ohio State University libraries. The *Disability Studies Quarterly* is unique among peer-reviewed academic journals because it is made available for free online (http://dsq-sds.org) to anyone with an internet connection who wishes to read it. The Society for Disability Studies experienced growth similar to that of the DSQ, going from a small collection of a couple dozen people during the early 1980s to a major international organization whose annual conference drew more than 500 participants in 2015. In addition to attending the annual meeting of the Society for Disability Studies, scholars, activists, and artists in countries other than the United States organized both formally and informally throughout the 1990s and into the twenty-first century, creating a global disability studies movement.

The number of degree programs and other initiatives that have flourished at colleges and universities throughout North America, Europe, and the rest of the world are a direct measure of the institutional growth of disability studies as an interdisciplinary academic field. In a study they characterized as conservative in its findings, Cushing and Smith (2009) found that for the 27-year period between 1981 and 2008, disability studies course offerings in English-speaking North America grew a whopping 922 percent. Cushing and Smith found that in the five areas they referred to as the Western, English-speaking world – the United States, the United Kingdom, Canada, Australia, and New Zealand – there were in 2008, 36 "full" disability studies programs, which they defined as programs offering a Bachelors, Masters, or Ph.D. in disability studies. There were an additional 31 "partial" disability studies programs that offered students modules, a minor, a diploma, a concentration, or a certificate. Disability studies degree programs, both partial and full, experienced a growth rate well over 200 percent from the late-1990s to 2008 (Cushing, Smith, 2009; Taylor, Zubal-Ruggieri, 2008). This phenomenal growth continued after 2008. A 2015 survey of disability studies degrees offered in the United Kingdom revealed 40 different programs. Also in 2015, the University of Toledo, Ohio launched the first full undergraduate major in disability studies in the United States. Administratively, most Disability Studies programs are located in primarily three general areas within colleges or universities: independent disability studies departments (primarily in the U.S. and Canada), hybridized disability studies programs that are integrated with other fields, including the applied fields (common in the U.S., Australia, and New Zealand), and disability studies programs that are integrated into existing liberal arts programs and departments (common in the U.K. and the U.S.) (Cushing, Smith, 2009).

Right now there is no single Disability Studies program or department in Poland and very few universities offer classes that familiarize students with Disability Studies scholarship. This is going to change soon: In October 2016 The Maria Grzegorzewska University in Poland will start the first MA program in Disability Studies in Poland. So far there is no BA program in Disability Studies, however that may change in the near future too. More importantly though, it is probable that in a few years Disability Studies will gain enough momentum in Poland that more schools and departments will include it in their curricula. The question is, which strategy would be the most successful option in Poland: independent disability studies departments, which are quite rare and currently only exist in the U.S. and Canada; hybridized disability studies programs that are integrated with other fields, including the health sciences or professional fields; or disability studies programs that are part of existing liberal arts departments? The history of gender studies departments in Poland reveals that independent studies programs can end up being isolated from more "mainstream" departments. The 2013–2014 debate or rather attack on "gender" started by the Catholic Church proved that gender studies departments in Poland do not have as big an impact on public debates their founders might have hoped, for even though gender studies experts engaged in those debates, it was mostly the Church who dictated the rules of public discussion.2) In an effort to avoid a fate similar to gender studies, it might benefit scholars to integrate disability studies curricula into existing liberal arts and social science programs and departments. This would help ensure that their faculty would not be isolated and would evidence the importance of disability studies and its connections with cultural studies, gender studies, sociology, philosophy, architecture, history, and other disciplines.

Integrating disability studies in the ways mentioned above would help to recruit faculty. Although some schools – mostly in the U.S. – employ scholars with PhDs in disability studies, most programs recruit their faculty from a number of older, more well-established disciplines, such as English, History, and Sociology, various

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2) http://www.krytykapolityczna.pl/artykuly/opinie/20131219/graff-gender-i-polityka-ale-ta-prawdziwa; http://www.mmpoznan.pl/artykul/panel-dyskusyjny-o-gender-zostal-odwolany,2738770,art,t,id,tm.html

Studies departments such as American, Cultural, Women's and Gender, Media, Design, and Science Studies, and fields such as architecture, occupational therapy, and education. The two elements that unite this diverse group of scholars are an overriding interest in disability and the lives of disabled people, and a strong commitment to using some variation of the social model of disability.

The Social Model of Disability

The social (occasionally called the socio-political) model of disability originated among disability rights activists in the United Kingdom in the early 1970s. Its primary purpose was to separate disability from impairment and say that disability was something that was socially created, while impairment was merely a biological fact with no cultural values attached to it. Under the social model, what became disabling for people was not their inability to walk, see, or hear (for example), but rather the inaccessibility of a physical, social, and cultural environment that remained hostile to their presence in it. As the British Union for the Physically Impaired Against Segregation (UPIAS) explained, disability is "a form of [socially created] disadvantage which is imposed on top of one's impairment, that is, the disadvantage or restriction of activity caused by a contemporary social organization that takes little or no account of people with physical impairments" (quoted in Tremain, 2006b, p. 187). Put simply, the social model of disability makes a critical distinction between impairment (body) and disability (society) and roots disabled people's limitations in societal barriers that disable them, not in any individual embodied deficit. Disability studies scholars refer to this form of exclusion as "ableism." They argue that ableism and ableist attitudes are present in all societies that are built by and for nondisabled people (Goodley, 2011, 2014).

For the next four decades (ca. 1975–2015), the social model of disability would form the core of the growing and evolving field of disability studies. Initially, primarily white male researchers who focused on physical and sensory impairments dominated disability studies in the United Kingdom and the United States. Throughout the late-1970s and most of the 1980s, sociologists and scholars using sociologically oriented methodologies sought to document and analyze both the causes and the effects of the structural exclusion of disabled people from society in areas such as employment, education, housing, and transportation. Over the remainder of the twentieth century and into the twenty-first century (ca. 1985–2015), disability studies scholars went from focusing almost exclusively on examining the effects of various social forces in the lives of people with physical and sensory impairments to including a much broader range of impairments and a much larger evidence (i.e. archival) base in their research. Disability studies scholars trained primarily in English and History, as well as other studies programs (e.g. American, Media, Women's and Gender) built on the foundational literature developed in the field's first decade (ca. 1975–1985) by exploring not only the representation of disability and disabled people in culture (e.g. literature, film, art, popular culture), but also the lived experiences of disabled people throughout history. This new generation of scholars, many of whom were women, racial/ethnic minorities, and disabled, and were influenced by feminist, queer, and critical race theory expanded the range of impairments under their purview to include "mental illness" – often referred to as madness by disability studies scholars – learning and developmental disabilities, and chronic illnesses (Goodley, 2011; 2014). By the first decade of the twenty-first century, the social model of disability had not only proven incredibly powerful in securing civil and human rights for people with disabilities (e.g. ADA, 1990, 2008; UNCRPD, 2008), it also revolutionized the ways in which a growing group of academics, artists, and activists thought about impairment and disability. As Bonnie Smith, professor of women's and gender studies at Rutgers University (USA), noted (2004, p. 1), "Gone are the days of a simple and dominant physiological or medical definition of disability."

By redefining disability as something created in the social world and not through biology (or genes or nuerochemistry), the social model of disability enabled scholars (and activists and artists) to move disabled people away from their historical place in society as individuals in need of medical, rehabilitation, welfare, and other services and interventions to that of an oppressed social minority in need of recognition of its civil and human rights. By discarding the notion that disability is negative and rooted in the individual, and by thinking critically about the power of various social arrangements to disable, social model theorists have been able to develop a powerful understanding of what it means to live differently in the world. Part of the success of the social model derives from its ability to expand the definition of disability to include a broad range of impairments, illnesses, and conditions, and to show that disability will touch everyone at some point in their life. Whether we become disabled or not, all of us at some point in our lives will feel the effects of disability, as we age, as we interact with co-workers, friends, lovers, clients, students, or customers, and as we care for the ones we love. The tremendous diversity among the world's disabled population and the broad range of experiences we all have with disability have been a source of empowerment for disability rights activists and academics alike.

While all disability studies scholars agree on the basic premise of the social model – that disability exists outside of the human body; that it is mediated through the environment and social relations – there are scholars who offer important critiques of some of the social model's finer points. These critiques can be broken down into three general categories, none of which are mutually exclusive (they all overlap). The first seeks to revise our understanding of the social model by critiquing the ways in which it defines impairment. The second values identity politics – as opposed to the more structural approaches of "strict" social model theorists – and urges us to recognize the critical role of class, race, gender, sexuality, and other categories in the formation of disabled people's identities and experiences. A third group of disability studies scholars who focus their work on "Global Disability Studies" question the usefulness of the social model outside of the five areas that Cushing and Smith (2009) referred to as the Western, English-speaking world – the United States, the United Kingdom, Canada, Australia, and New Zealand. In the next section we will briefly address each one of these critiques of the social model of disability.

Critiques of the Social Model

As stated above, the social model defines impairment as neutral, as a biological reality that exists outside of social relations, politics, and the pathologizing discourses of Western medicine. Initially, disability studies theorists drew an analogy with feminist thinking about sex and gender to describe the difference between impairment and disability: *impairment is to sex as disability is to gender*. Early disability studies theorists held that impairment, like our biological sex, is fixed in our bodies. We have little if any power to control or alter our impairment. It is part of our being, part of who we are; it is real. Disability, on the other hand, is like gender. It is socially created and historically contingent. Because disability emerges out of the built environment and the social milieu within which we live, it changes over time. Disability like gender is fluid. We have the power to control what becomes disabling in society by altering the built environment, as well as dominant social relations and cultural perceptions. Disability studies theorists through their research and writing seek to promote change in all three areas related to disability – the built environment, social relations, and cultural perceptions.

By the 1990s, feminist and queer theorists from a number of academic backgrounds, including those in disability studies, began challenging the taken-for-granted nature of both biological sex and impairment. They argued that neither is as fixed or as value free as we might assume. Ideas and definitions of both sex and impairment change over time and among cultures. A mental illness in one time and place might be a blessing from the gods in another time and place. A missing limb or a lack of sensory perception could evoke stigma and feelings of shame and guilt in one setting and be completely normative in another. One need only look at the shift from "mental retardation" to learning and developmental disability at the end of the twentieth century, or the astronomical rise in psychiatric "disorders," such as autism at the beginning of the twenty-first century to see the fluidity of impairment categories. A person could be defined as impaired in one historical moment and considered unimpaired in another historical moment. The history of the USSR and communist Poland and their practices of labeling and confining political dissidents in institutions for people with mental disabilities confirm the instability and complexities of mental illness diagnoses. In other cases, people with certain types of impairments might also only experience them sporadically and in varying degrees over the course of their lifetime. Think for example of someone with multiple sclerosis, lupus, chronic fatigue, or another chronic condition who might have days, weeks, or even months in which they are relatively "symptom-free." Finally, disability studies theorists declared that impairment, in most cases, has very real disabling effects in the lives of those individuals who live with it. They urged social model theorists and all disability studies scholars to reconcile themselves with the fact that impairment – that is people's own bodies – can impose very real restrictions on their lives and in some cases those impairments can be deadly. No amount of social activism can alter the lived effects of impairment in some people's lives. Scholars in disability studies refer to these lived realities as the effects of impairment, or impairment effects.

The second critique of the social model has its roots in a particular form of US identity politics (Rembis, 2010). Authors writing primarily in the United States argue that a stigmatized and devalued disability identity is one of the powerful legacies of the individualization, medicalization, and pathologization of impairment under the Western medical model of disability (Siebers, 2008). The general argument is that disabled people are divided by their impairment, by medical and rehabilitation professionals, social workers, educators, and a larger society that sees them as nothing more than their own individual impairment(s) and treats each one of them as an individual case, patient, or client, different from all other cases, patients, or clients. The professionals can find similarities in disabled people's physiology, their neurochemistry, their symptoms, but disabled people remained isolated and alone, trapped by their own internalization of a depoliticized, pathologized, individualized, and ultimately devalued sense of themselves. Only when disabled people shed this stigmatized identity can they become free to see the ableist world and their place within it for what it really is – only then can they see the discrimination, segregation, isolation, and outright violence and oppression that they face every day.

According to this liberal form of identity politics, disabled people become empowered when they embrace their disabled identity and make it their own; when they begin to associate, demonstrate, and identify with other folks who have done likewise. Once they have experienced this consciousness raising, they are(in most situations) able to live life on their own terms. Some of them choose to "let their freak flags fly." Some flaunt their (impaired) bodies and revel in their sexuality. Others among them choose to "pass," to minimize the extent of their impairment or mute their disabled identities (usually when in the presence of mixed company). Most disabled people, however, choose to live what prominent disability studies theorist Tobin Siebers (2008) calls a "complex embodiment," which is some mix of all of these extremes. Within this framework, everything disabled people choose to do, every utterance they make, and every cultural artifact they produce gets politicized. The personal lived experience of disability becomes a politicized identity that can be used to enact social and legal change (Siebers, 2008).

Critical to this identity-based disability politic and to its attendant theorizing within disability studies is the notion of "intersectionality." As Siebers (2008) argues, disabled people experience a complex embodiment. Their embodied experience in the world is influenced not only by their impairment or the disabling effects of an ableist society, but rather by the complex interactions – intersections – of impairment, disability, race, class, gender, sexuality, religion, and other important social and cultural categories. In Poland, the recent case of Wioletta Szwak serves as an example of this type of intersectionality. In 2009, Wioletta Szwak gave birth to her eighth child and was sterilized right after giving birth without a chance to give or to deny her consent to the procedure.3) The doctor claimed that she performed the sterilization to save Szwak's life. According to the doctor, a potential next pregnancy could pose a serious threat to Szwak's health and life.4) The evidence presented a few years later in court showed that from a medical perspective the sterilization was illegal, because Wioletta Szwak's life was not in danger and sterilization without consent is legal in Poland only when it saves a patient's life. Articles that appeared after Szwak took the case to court mentioned that Szwak was poor and possibly "mildly mentally disabled."5) What precisely compelled the physician to perform the sterilization: poverty, gender, "mild mental disability," or some combination of all of these factors?6) Wioletta Szwak's case is important, because it unmasks the entanglement of class, gender, age, and disability. Almost every article about her mentioned that she and her husband were poor, "simple," and "untidy." Thus, the implication goes, having eight children is an irresponsible choice for certain people. Only people who are "tidy" and "not simple" should have children. Journalists commented on Szwak's age, stating that she "is not the youngest one," which could be a comment on her "carelessness," or an implicit argument against the production of disabled babies, which are more common among older women. Additionally, from the articles the readers find out that Szwak's husband is "over 60," which makes him, apparently, unfit to be a father. We did not find an article in which

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3) Some articles mention it was Szwak's ninth pregnancy.

4) http://www.gloswielkopolski.pl/artykul/3636540,sterylizacja-wioletty-szwak-lekarka-nie-trafi-do-wiezienia,id,t.html

5) http://wyborcza.pl/1,75478,16926723,Sterylizacja_Wioletty_Szwak_byla_nielegalna__lekarka.html

6) http://www.humanityinaction.org/knowledgebase/113-a-dangerous-compromise-the-battle-of-reproductive-rights-in-poland. What is striking is that the Polish feminist movement which is engaged in the battle over Polish extremely restrictive law concerning the right to abortion, promotes sexual education, and participates in public debate on reproductive rights did not pay much attention to Szwak's story even though her reproductive rights, similarly to many women who were denied legal abortion, were violated.

Szwak commented on her own (alleged) disability, but the journalists insisted on using language that suggests that she is, in fact, mentally disabled, which supposedly made the sterilization decision legitimate.[7] According to news reports, at some point during the lawsuit, which lasted a few years and ended in 2015, the judge said that if Szwak had not been sterilized, she would have had another child, implying that the decision made by the doctor was indeed an appropriate one.[8] Here, an intersectional analysis has the potential to show who in Polish society is deemed fit to have children and who is not, and points to disability, class, age, and gender as determining factors. Disability studies scholars interested in identity and identity politics argue that all disability studies research must take into account important and sometimes conflicting subjectivities when documenting and analyzing disability in history and in culture, and in the daily lives, loves, and experiences of disabled people.

The final major critique of the social model to emerge within disability studies comes from scholars interested in global disability studies. Put simply, disability studies scholars working outside of the Western English-speaking world, or what they alternatively refer to as the global North, are finding that disability studies theories that are dominant in the West or global North, including the social model, are often ineffective, or in some cases only partially effective, in helping to explain the lived experiences of disabled people in other parts of the world, or what they call the global South. Global disability studies theorists make strong arguments for avoiding the uncritical exportation of global North disability studies theories to the global South, and for situating analyses of the lived experiences of disabled people in their own local cultural and historical contexts, social relations, and governing structures, as well as larger international political and economic systems. Rather than dismiss global North disability studies, global South scholars encourage collaborative and constructive dialogue between North and South, which they argue will build stronger disability studies analyses and more powerful disability politics in both parts of the world (Mehrotra, 2013). However, it seems that global North and global South disability studies do not

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[7] http://www.polityka.pl/tygodnikpolityka/spoleczenstwo/301972,1,rodziny-z-problemami.read; http://www.gloswielkopolski.pl/artykul/1069856,szamotuly-lekarka-skazana-na-rok-w-zawieszeniu-za-sterylizacje-wioletty-szwak,id,t.html; http://wiadomosci.wp.pl/kat,1329,title,Poddana-sterylizacji-Wioletta-Szwak-domaga-sie-pol-miliona-zl-odszkodowania,wid,15016664,wiadomosc.html; http://www.gloswielkopolski.pl/artykul/668615,wioletta-szwak-zada-pol-miliona-odszkodowania-za-sterylizacje,id,t.html; http://www.gloswielkopolski.pl/artykul/3636540,sterylizacja-wioletty-szwak-lekarka-nie-trafi-do-wiezienia,id,t.html; http://poznan.wyborcza.pl/poznan/1,36001,15158075,Sterylizacja_Wioletty_Szwak_nielegalna__Lekarka_skazana.html; http://www.gloswielkopolski.pl/artykul/668615,wioletta-szwak-zada-pol-miliona-odszkodowania-za-sterylizacje,id,t.html

[8] http://poznan.wyborcza.pl/poznan/1,36001,10290356,Bo_znow_by_zaszla___sad_o_sterylizacji_Wioletty_Szwak.html. Szwak and the hospital reached a settlement. The amount of money Szwak received is unknown.

encompass Eastern European disability studies. Critically important to our discussion here is the question of Poland and its geopolitical position. It is important to point out that the division between North and South itself poses a problem for Polish disability studies: does Poland belong to the global North or South? Where do we locate Eastern Europe and post-USSR republics? It seems that Eastern Europe with its history of dependency on the USSR, but not necessarily a history of colonization (depending on the country), requires a new model that includes this region. If that is the case, Eastern European disability studies might differ significantly from both global South and global North disability studies, for the histories of nonnormative bodies are shaped there by circumstances that do not necessarily overlap with the legacies of colonization and imperialism experienced by people in other parts of the world.

Disability Studies in Poland

Poland is an ideal location to build disability studies. Disability activism and advocacy – the critical foundation necessary to support disability studies – is growing in Poland, but not without its problems. The website of the Government Plenipotentiary for Disabled People lists 35 nongovernmental organizations (NGOs), mostly established after 1989, which are concerned with issues related to disability (niepelnosprawni.gov.pl). Most of these organizations can be considered advocacy organizations. They (problematically) use paternalistic, “expert,” “helping,” and in many cases religious rhetoric to promote increased opportunities for people with disabilities primarily in employment. The unemployment rate of 17.9% among Poland’s estimated 4.7 million people with disabilities is significantly higher than that of the non-disabled working-age population, which was 11.3% in October 2014. One of Poland’s largest and oldest disability NGOs, Integracja, formed just before Poland implemented its Charter of Fundamental Rights of Persons with Disabilities (August 1997), takes a more holistic approach to its advocacy and activist work, focusing on education, integration, the removal of social barriers, employment, and raising public awareness. Yet even it cannot escape some of the patronizing rhetoric of the majority of Poland’s disability NGOs, positioning disability as something to be avoided rather than embraced and calling on the larger society’s “willingness to help” disabled people (integracja.org). Despite the problematic approach that many NGOs take toward disability advocacy, a sentiment in favor of disability rights is clearly growing in Poland.9) This is further evidenced by the adoption of the United Nations

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9) One reason for this approach might be a desire among Polish disability NGOs to portray disabled people as the ever-grateful “good cripple,” as opposed to the demanding “angry cripple,” insisting on the enforcement of her civil and human rights. For a discussion of the “good cripple” see Johnson, Mary. *Make Them Go Away: Clint Eastwood, Christopher Reeve, and the Case*

Convention on the Rights of Persons with Disabilities (UNCRPD) in June 2012 and the creation of the political party Together for the Disabled in July 2015.

Despite the growing recognition of disability issues in Poland, a recent caregiver protest in Warsaw attracted little attention from the larger public. Among many demands made by protesters, the most widely discussed one concerned the amount of money the caregivers, who often gave up their jobs, received in order to take care of dependents. In contrast, in summer 2007, more than three thousand nurses met in Warsaw. They camped for several weeks near the Parliament building in tents that became known as "the white town."10) The protestors in white town found allies among other professional groups and lay people.11) Celebrities came to white town to support the nurses.12) In a show of support, the mayor of Warsaw refused to call the protest "illegal" and refused to close down white town.13) Many of those who supported the nurses characterized the nurses' cause as a labor concern: everyone benefits from better working conditions in hospitals. Unlike the nurses' protest, when the caregivers of disabled people protested in 2014 and 2015, few people who were not immediate relatives of disabled people joined them. The caregivers' protest, in contrast to the nurses' protest, revealed three fundamental concerns related to disability: the absence of an organized disability rights movement, a general lack of interest in the protest by people who were not immediate relatives and caretakers of disabled people, and the state's belief that families should be predominantly responsible for the care of disabled people. Already the name of the protest – the caregiver protest – points out that disabled people in Poland did not form a meaningful part of the movement. Instead, their caregivers remained at center stage.

Some explanations for the reluctance among Polish citizens to embrace disability rights issues might be rooted in peoples' unwillingness to acknowledge their own dependency on a variety of caregivers. Even though many disability studies scholars insist, as we have argued in this article, that we all have intimate connections to disability and disabled people, the citizens of Warsaw and other cities in Poland did not identify with the caregivers' cause. As Rafał Bakalarczyk points out in the interview "Gdzie Ta Solidarność?" ("Where is the Solidarity?") caregivers and their dependents form an isolated and abandoned group in Polish society. Some feminist organizations did indeed support the caregiver protest. Yet there was a general lack of allies and solidarity with

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Against Disability Rights. Louisville: Avocado Press, 2003 and Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York University Press, 1998.

10) http://www.krytykapolityczna.pl/artykuly/zdrowie/20140327/rodzicie-niepelnosprawnych-dzieci-jestesmy-tu-z-rozpaczy-nie-z-nudow

11) http://wiadomosci.wp.pl/kat,1342,wid,8980431,wiadomosc.html

12) http://www.lewica.pl/?id=14169

13) http://www.tvn24.pl/wiadomosci-z-kraju,3/biale-miasteczko-ma-byc-zlikwidowane,27314.html

disabled people themselves during the protest, and this general lack of support has been visible in other areas as well. Both feminists and the growing LGBTQ movement (Lesbian, Gay, Bisexual, Transgender), who have been strong allies in other parts of the world and who in Poland organize annual marches and protests, seem to be reluctant to engage in meaningful ways with disabled people. The situation may be changing, however.[14] The feminist organization responsible for the March 8th annual protest, Porozumienie Kobiet 8 Marca (Coalition of the Women of the 8th of March), prepared in 2015 a video in Polish sign language promoting the event and inviting Deaf people to join the march. Polish women with disabilities are becoming more visible and are increasingly included within the feminist movement. Yet their presence remains problematic. Material inequities, for example, remain largely unaddressed. The lack of material support for caregivers and the protests that it engendered reveal in stark clarity the second-class citizenship of disabled people in Poland and the perception that their needs are irrelevant and better met within the private sphere of the family by low-paid caregivers.

As the organizations and the protests cited here reveal, there are traces of disability studies (and disability rights) emerging in Poland. Examples include, the publication in 2010 of a special issue entitled, “Disability as a Political Category,” in the quarterly publication of the Institute for the Development of Social Service and “Ugly bodies: Queer Perspectives on Illness, Disability, and Aging,” a forthcoming 2015 issue of the academic journal *InterAlia*, which might be the first humanities journal to take up disability studies in Poland. In recent years, there have also been courses in disability studies that explore everything from architectural barriers to the intersection of gender and disability taught at the Jagiellonian University and at Warsaw University. In 2013–2014 three Polish universities (the Jagiellonian University, University of Warsaw and University of Science and Technology in Cracow) organized a project entitled “Polish Disabled,” which was financed by the National Fund for the Rehabilitation of Disabled People. The goals of the project were to prepare an assessment of the social and economic situation of the disabled population in Poland and on the basis of that evaluation prepare recommendations concerning social policy changes relating to disabled people. The project consisted of workshops for disabled people, NGOs, and people working in public institutions. The team organizing the project conducted extensive research and collected both qualitative and

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14) A Polish feminist disability movement remains to be organized and Polish feminist disability studies remains to be written. One of the biggest Polish feminist disability studies topics will be the issue of abortion. Since Polish law is very restrictive and allows abortion in very few specific situations Polish feminist movement has been engaged for years in the fight to change it and the right to abortion remains one of its central demands. Therefore, it might be a challenge to write Polish feminist disability that takes up the issue of abortion from disability studies perspective.

quantitative data. They published articles in various magazines and journals and prepared their own publication presenting their methodology, perspective, and results. As a part of the project, they organized a two-day conference called, "Polish Disabled" in Warsaw in 2014. The team was interested in six areas: the effectiveness of social policy; the roots of successes and failures of the projects organized by different institutions supporting people with disabilities; how to increase the employment of disabled people; how to find a first job, good practices from Poland and abroad; the representations of disabled people in media; and the gendering of disability. Clearly disability studies is on the rise in Poland. However, it often seems incremental and somewhat epiphenomenal. Disability Studies as a discipline does not exist yet in Poland; instead, what we observe right now are "disability studies initiatives," which lack the framework that lies behind Disability Studies as an academic field. In the remainder of the article we offer a sampling of what could be considered "Polish Disability Studies" by engaging with some of the scholarship emerging out of the humanities. Our hope is that this will initiate further dialogue.

To date, authors writing about disability in Poland from a humanities perspective have focused mostly on literature and film. In Pamuła's own work on Polish young adult literature produced between 1945 and 1989, she has found a rich imagery that reveals that family constitutes the main site of disability rehabilitation and overcoming disability. In works such as *Beethoven and Jeans* (1968) and *Fotoplasticon* (1969) by Krystyna Siesicka, *Meeting by the Sea* (1962) by Jadwiga Korczakowska, and *The Whirlwind and Canes* (1959) by Irena Krzywicka rehabilitation takes place at home or by the sea, not at hospital, and the medical establishment cannot replace family. It is relatives who have the power to cure and it is the language of paternal and familial love that holds the key to one's overcoming disability. In much of this literature, the reliance on family during rehabilitation signals the weakness of the state. While the Polish communist state, from the perspective of young adult fiction, is a state of nondisabled people where disability often functions as a sign of moral deviancy or laziness, the state does not present its citizens with many opportunities for rehabilitation. In Irena Krzywicka's *The Whirlwind and Canes*, for example, a doctor helps the main protagonist, Michał, to recover from a car accident, but it is his family and friends who are ultimately responsible for his well-being. In *Beethoven and Jeans*, Krystyna Siesicka reveals the insufficiency of Polish medical care by creating the figure of a Swedish doctor who performs eye operations. Siesicka's protagonist, Piotr, is blind and even though in the end it is the doctor from the West who symbolizes the hope of regained sight, it is Piotr's fiancée who motivates him from afar to get the operation and organizes the surgery. Piotr and his fiancé live in different cities and see each other once a year. Throughout the year they send letters to each other. One function of their separation is to secure their sexual abstinence. This way, Siesicka makes clear that a heterosexual romance is a reward for overcoming disability. In other words, the romance can take place only when disability is evacuated.

In the context created by the young adult fiction evaluated in Pamuła's work, overcoming disability is, inherently, a family project. No one overcomes disability individually in Poland. Moreover, only nondisabled people deserve to form their own families, as the sterilization of Wioletta Szwak cited above exemplifies. Thus, literature reflects and refracts social reality and confirms to Ato Quayson's assertion in *Aesthetic Nervousness. Disability and the Crisis of Representation* that "there is no doubt that literary representation of disability somewhat subtends real-life treatment of disabled people" (30). Disability in Polish young adult novels operates, as Alison Kafer states in *Feminist Queer Crip*, "as the sign of the future of no future" (34), where nondisabled status and the eradication of disability secure the future of the family and by extension the nation. In these contexts, the literary history of disability in communist Poland is intimately bound up with the history of family and is critical in reproducingable-bodiedness, Polishness, communist values, and heterosexuality. The pervasiveness of the family motif does not end with the fall of communism in 1989. A brief review of post-1989 popular TV shows and literature reveals that the family institution remains dominant in Poland and continues to replace other forms of communal life and relationality.

Not surprisingly, the main site of interaction in Polish TV shows – including those featuring disabled characters – is the family. In his study *Niepełnosprawni i Niepełnosprawność w Mediach* (*Disability and Disabled People in Media*) Tomasz Sahaj mentions at least several recent and very popular shows that include disabled protagonists, e.g.: *Klan (The Clan)*, *Barwy szczęścia* (*The Colors of Happiness)*, *Samo życie* (*That's Life*), *M jak Miłość* (*L as Love*), *Doręczyciel* (*The Delivery Man*), *Plebania* (*Presbytery*). With their emphasis on the many "successes" of disabled people, these shows do not reflect the social reality of disabled people in Poland. Sahaj (2013) cites Beata Łaciak who notes that physically disabled people, usually wheelchair users who are the most popular group of disabled people featured in Polish TV shows, do not struggle financially, they graduate from universities, they find employment, they do not face architectural or environmental obstacles, and they enjoy happy marriages and relationships (always heterosexual). Even if a romantic relationship is not contingent on the disappearance of disability – as in the young adult literature – it is consistently a heterosexual one, and a disabled character's children are always nondisabled. In contrast with pre-1989 literary and cinematic works, overcoming disability or rehabilitation is not the biggest life aim of disabled characters. The most common problems disabled people in Polish TV shows experience are psychological ones, other than that disability as a topic does not exist.

This may be a strategy of familiarizing viewers with disability that TV producers believe is the safest and most successful one. However, it is a strategy that ultimately erases disability as an experience, in part because it resists the fact that the material realities and lived experiences of disabled people in Poland, as the employment statistics show, differ significantly from nondisabled lives. The common approach to disability used by TV producers is a strategy that does not problematize disability and its social consequences. Łaciak mentions that for years *The Clan* creators would not discuss Maciek's (a character living with Down syndrome) largely social problems (Sahaj, 2013). It seemed that living with Down syndrome had no consequences in his life. The moment when producers decided to show that Maciek could not get married – city officials refused to marry two mentally disabled people and the law in fact supports their decision – was considered a major breakthrough in the representation of disability on television. Despite this small victory, many challenges still face television producers in Poland. For example, most disabled characters are played by nondisabled actors and actresses, and mental and cognitive disability are still rarely portrayed on Polish TV. Additionally, *Chce się żyć* (*Life Feels Good*) (2013), the most popular Polish movie about a disabled person in recent yearsstill takes up the topic of rehabilitation. The main character, who lives with cerebral palsy, learns how to communicate and this way proves his humanity. The main protagonist's struggle is the struggle for dignity and masculinity and learning how to communicate. In other words, he is struggling with becoming "less" disabled and more "able-bodied." Importantly, he proves his manliness and heterosexuality by showing erotic interest in his nurses and the female volunteers who come to the hospital in which he lives. The representations here of one disabled person's love and sexual desire are important. Yet the highly stylized, exaggerated manner of showing it in *Life Feels Good* borders on condescending ridicule of disabled sexuality and additionally produces a misogynistic undertone. Dawid Ogrodnik, the nondisabled actor who plays the main character in the show, might be praised for his acting prowess, but in the end his is a performance that reveals the lengths to which the disability rights movement in Poland must go to achieve equality.

In another popular literary work, the eradication of disability is critical to the maintenance of family. Dorota Terakowska's widely read novel *Pupa* (*Poczwarka*) from 2001 tells the story of a married couple and their daughter who lives with Down syndrome. The metaphoric title refers to a disabled person and points to the (stereotypical) binary of the external vs. internal beauty and transforming qualities of disability; from a pupa to a butterfly. The couple impatiently awaited the birth of their first child, but when she was born they were not happy. They, like most couples, wanted a nondisabled child. The narrative focuses on the ways in which they struggle to accept their daughter's disability and finally learn how to love and care for their child. Simultaneously, Terakowska offers an alternative narrative told from the disabled child's point of view who is understanding and warm (in other words: human), but does not have the means to express what she thinks and feels. When the parents finally learn to love their child, she dies. The death of a disabled child seems to be the only logical and desired ending, for disability is just a pretext here to tell a story about two successful middle aged parents for whom a child is part of a (failed) business plan. In *Narrative Prosthesis. Disability and the Dependencies of Discourse* David T. Mitchell and Sharon L. Snyder comment that oftentimes in literature "disability's very unknow ability consolidates the need to tell a story about it" (6) and Dorota Terakowska's novel does not differ much in this regard from the American and European writings Mitchell and Snyder analyze in their text. In her book disability functions in a twofold manner: first it operates as "the impetus to narrate a story" (10) about a successful couple who does not know what is truly important in life; second it symbolizes a fundamentally different, separate from "normal" human experience. Mitchell and Snyder argue that various disabilities in literature "have been narrated as alien to the normal course of human affairs" and *Poczwarka* fits their description. Before the novel ends, the wife gets pregnant again and this time the couple is gifted with a nondisabled child. Through this "transformation," *Pupa* offers no future for the disabled character; the only future of the disabled child is death, or no future at all. Through her novel, Terakowska teaches readers that a disabled character's sole role is to show adults how to love *odd* children or children that might be unwanted. The presence of disability teaches the main characters how not to be selfish, and when their child's mission is completed her life ends, for disability was not the author's main preoccupation in the first place. The topic was the transformation of the parents that disability merely facilitated. This way the narrative reveals its dependency upon disability, as Mitchell and Snyder have argued for other important texts in the Western canon. In *Poczwarka*, disability is not only undesired, but there is literally no place for it in the married couple's life and for their efforts in loving they are rewarded with a nondisabled child. This way, disability facilitates the creation of the nuclear family, which in turn secures the future of the (able) nation.

In 2002, Anna Sobolewska, a professor at the Polish Academy of Sciences, published a memoir, *Cela: Odpowiedź na zespół Downa* (*Cela: A Response to Down Syndrome*) about her family's experience living with Down syndrome. It is a very different account. Even though Sobolewska shares with readers her anxiety about Cela's (her daughter) future, it is a book that proves that disabled life is not one-dimensional and its exclusive goal is not limited to teaching adults a life lesson. Cela has her own interests and friends and resists the label of "Down syndrome." She coined her nickname "Cela" herself. Sobolewska relies sometimes on a quasi-religious discourse and her husband compares Cela's face to Buddha's face, but they do respect her autonomy and recognize her as a separate human being who cannot be defined only by her disability. At the same time the author discusses the stigma attached to people with Down syndrome and the shame she experienced as a mother of a disabled child. This way, it is a book not only about her daughter, but a family experience of living with disability in a society that medicalizes and hides disabilities. Sobolewska's account is especially critical when she describes her encounters with doctors who after she gave birth to her child asked her several times why she did not do prenatal screening, implying that abortion of a disabled fetus might have been a more appropriate choice than to give birth to a daughter with Down syndrome (Sobolewska explains she did not do the screening on purpose; she did not want to make a decision whether to terminate a pregnancy if it turned out that the fetus was disabled). Sobolewska is not a disability studies scholar, her repeated use of the words "normal" or "defect" reminds one of this, nevertheless, her account shows a sensibility that, to a certain extent, would be familiar to many people who define themselves as such.

Conclusion

Disability Studies experienced tremendous growth in its first forty years. Born out of the disability rights movement primarily in the United Kingdom and the United States, Disability Studies took the social model of disability as its basic tenet. A direct critique of the older medical model of disability, the social model separated impairment from disability and stated that the built environment, social relations, and dominant cultures disabled people, not necessarily their own bodies. Disability Studies scholars raised important and influential critiques of the social model that served to broaden the reach of the field to include a greater number of disability experiences and strengthen the theoretical and methodological foundations upon which arguments were built. As Disability Studies entered the twenty-first century, scholars from a number of areas within the field increasingly critiqued its primary focus on white citizens of the Western, English-speaking world, giving rise to a growing global disability studies movement. Given the robustness of research emerging from Disability Studies and the impressive institutional growth of the field in most parts of the world, there is little doubt that it will continue to be influential in a number of academic, social, political, and cultural areas in the future.

At this point it is uncertain how influential Disability Studies will turn out to be in Poland. The various initiatives indicate that agrowing number of scholars across disciplines show interest in Disability Studies, but so far their projects remainlargely unified in both their philosophy and their approach. As the disability rights movement and disability studies mature in Poland, they will no doubt become more systematic in their Disability Studies thinking and framework. Institutional support – some sort of Center for Disability Studies affiliated with one of the Polish universities – would be of extreme importance in achieving this more systematized unified approach to disability studies. Disability Studies programs in Poland might follow Western examples, but as we have revealed, Poland and other Eastern European countries will no doubt offer new ways of thinking about disability and integrating Disability Studies scholarship into already existing curricula. Disability Studies might, for example, help to rethink pronatalist discourses and the institution of the family in Poland. The analysis of representations of disability in Polish literature and cinematic and television works suggest that while disability remains medicalized and privatized, it does extend beyond an individual body when it becomes a family affair. It will be fruitful for the nascent Polish disability studies movement to analyze the family living with disability.

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DISABILITY STUDIES: A VIEW FROM THE HUMANITIES

Abstract

In this essay, Rembis and Pamuła explore the state of the field of disability studies, making special note of its relevance to the study of disability in Poland. Special consideration is given to the critical importance of the dialectical relationship between disability activism and lived experiences and the growth of disability studies as an academic field.

Disability and disability rights have become global concerns. Since the 1970s, disabled activists and their allies in countries around the world have been working to redefine disability and secure the rights of disabled people. The disability rights movement consists of direct action protests, legal challenges, advocacy, and education. An outgrowth of this diverse movement has been the rise of the interdisciplinary field of disability studies. In this essay, we will offer a brief overview of disability studies, highlighting the importance of the "social model" of disability and the critiques it has engendered. We will then turn to a discussion of "global disability studies," focusing specifically on Poland, revealing the fruitful ways in which insights from the humanities can be brought to bear on the lived experiences and filmic and literary representations of disability and disabled people.

Key words: disability studies, disability, humanities, disability rights

STUDIA NAD NIEPEŁNOSPRAWNOŚCIĄ. PERSPEKTYWA HUMANISTYCZNA

Streszczenie

W prezentowanej pracy Rembis i Pamuła badają stan studiów nad niepełnosprawnością, zwracając szczególną uwagę na jego związek ze stanem studiów nad niepełnosprawnością w Polsce. Autorzy kładą nacisk na decydujące znaczenie dialektycznego związku między aktywizmem w zakresie niepełnosprawności i przeżytymi doświadczeniami a rozwojem studiów nad niepełnosprawnością jako dziedziny akademickiej.

Niepełnosprawność i prawa osób niepełnosprawnych stały się problemami ogólnoświatowymi. Od lat siedemdziesiątych ubiegłego wieku niepełnosprawni aktywiści oraz ich sojusznicy na całym świecie podejmują działania w celu przedefiniowania niepełnosprawności i zapewnienia praw osobom niepełnosprawnym. Ruch na rzecz praw osób z niepełnosprawnością to bezpośrednie akcje protestacyjne, sprzeciwy sądowe, orędownictwo i edukacja. Następstwem działań w ramach tego różnorodnego ruchu stało się powstanie interdyscyplinarnej dziedziny studiów nad niepełnosprawnością. W niniejszej pracy autorzy przedstawiają studia nad niepełnosprawnością w ogólnych zarysach, podkreślając znaczenie „społecznego modelu" niepełnosprawności oraz krytykę, której stał się źródłem. Następnie omawiają „globalne studia nad niepełnosprawnością", koncentrując się w szczególności na Polsce i ukazując obiecujące sposoby zastosowania spostrzeżeń z dziedziny nauk humanistycznych dla zrozumienia przeżytych doświadczeń, a także filmowych i literackich interpretacji niepełnosprawności oraz osób niepełnosprawnych.

Słowa kluczowe: studia nad niepełnosprawnością niepełnosprawność, perspektywa humanistyczna, prawa osób niepełnosprawnych